



STRENGTHENING DIVERSITY IN RESEARCH PARTNERSHIPS:

Knowledge to Action Guide

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FAMILY-CENTERED CARE®

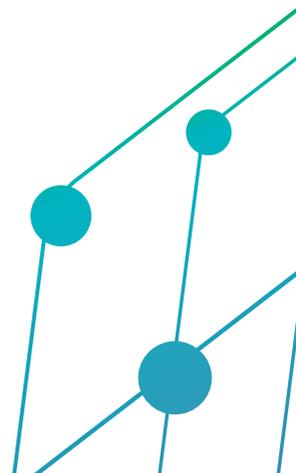
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Additional Resources

Spotlight Videos were produced from site visits to exemplary organizations that partner with diverse individuals and communities and interviews with researchers and patient, family, and community partners at IPFCC's **8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities**. You can view these at [Strengthening Diversity in Research Partnerships](http://ipfcc.org/bestpractices/strengthening-diversity/index.html).

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EXECUTIVE SUMMARY

Understanding the Problem

Diverse, vulnerable, and underserved populations are under-represented as participants in health care research. Lack of representation of diverse groups limits the generalizability of research and may also significantly contribute to health disparities. Authentic partnerships with under-represented communities in all stages of research represent a key strategy to address the inequity and disparities. Collaborative models of research, such as community-based participatory research (CBPR), offer methods for engaging diverse groups in research. However, CBPR is a relatively recent approach used in health care research and has not been widely adopted. To support partnerships in research and broader adoption of collaborative approaches to research, researchers need guidance to change the long-standing culture and beliefs in academic and research centers that may lead to reluctance or inability to collaborate with diverse patient, family, and community partners (PFC partners).

Project Background

In 2017, the Institute for Patient- and Family-Centered Care (IPFCC) received a two-year Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) for the project, **Strengthening Diversity in Research Partnerships: Knowledge to Action**. This funding supported two major efforts:

- Special programming at IPFCC's *8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities* held in Baltimore, MD in June 2018 featuring partnerships with diverse and underserved communities in health care research; and
- Development of a Knowledge to Action Guide and Resources providing guidance and best practices for creating partnerships with typically under-represented PFC partners in research. The Guide includes content gleaned from:
 - An extensive literature review
 - Consultation and input from a project Expert Advisory Panel comprised of researchers, health care professionals, and diverse PFC partners
 - Interviews with experts who are involved in partnerships in health care research

“As academic health centers seek to expand their goals to embrace a model that promotes health as well as health care, it is imperative to integrate community-engaged research.”

McElfish et al., 2015

- Conference presentations
- Site visits to three exemplary programs that authentically partner with diverse and vulnerable populations in research

While a collaborative approach to health care research has not been widely adopted, we learned through the project activities that there are researchers and PFC partners across the country committed to partnerships to plan, conduct, and disseminate research. We are grateful to the researchers and PFC partners for sharing their knowledge and insights and helping us build an understanding of how to advance partnerships with diverse PFC partners in research.

Overview of the Guide

To achieve its aim of conducting patient-centered outcomes research, PCORI created the PCORI Engagement Rubric, as a framework to offer concrete ways to operationalize engagement that incorporates patients and other stakeholders in all phases of research. The framework includes Principles of Engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating research; engagement activities; and examples of promising practices from PCORI-funded projects (Sheridan et al., 2017).

Building on the foundation of the Rubric, the Strengthening Diversity in Research Partnerships project team expanded the original Principles of Engagement to recognize and address the unique circumstances that arise when partnering with diverse and typically under-represented communities in research. This expansion was based on the lessons learned about meaningfully and authentically engaging these communities from researchers, clinicians, and PFC partners who participated in project activities (see the table listing the expanded Principles and Strategies on page 11 of the Guide).

Principles of Engaging Diverse PFC Partners in Research

- Trust
- Reciprocal Relationships
- Honesty
- Transparency
- Cultural Competency
- Co-Learning
- Partnerships

Each section of the Guide presents one of the seven principles and offers an Overview, Strategies and Insights, Stories from the Field, Top Tips, and Selected Resources. The Guide offers practical guidance to learn about, facilitate, and strengthen engagement of diverse PFC partners such that research can be co-designed and co-implemented and we can move forward toward the elimination of health disparities.

Conclusion

It was clear from all of the experts—patient, family, and community partners and researchers—who shared their wisdom that developing meaningful and authentic partnerships takes leadership, time, resources, flexibility, and most importantly, a firm commitment to be open to learning from each other. By engaging in true partnerships we will be better equipped to design and conduct research that ultimately leads to knowledge benefiting all and fostering the elimination of disparities existing in health and health care.

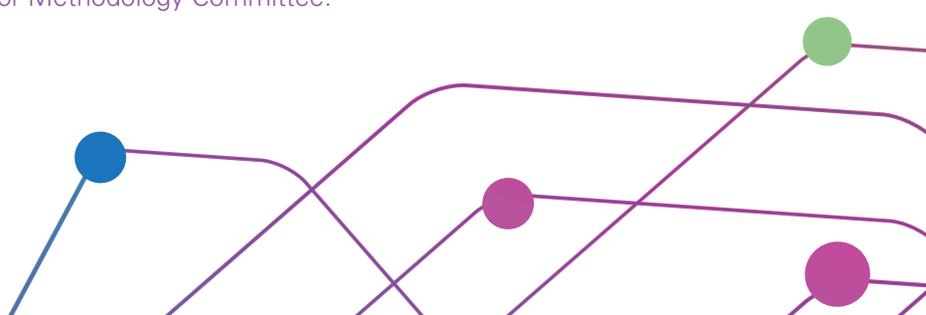
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Additional Resources

Spotlight Videos were produced from site visits to exemplary organizations that partner with diverse individuals and communities and interviews with researchers and PFC partners at IPFCC’s **8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities**. You can view these at [Strengthening Diversity in Research Partnerships](#).

This project was funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (EAIN-4421). The views and statements presented in this report are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.



INTRODUCTION

Understanding the Problem

For decades, diverse, vulnerable, and underserved populations have been under-represented as participants in health care research. This inequity goes beyond race and ethnicity and includes populations such as LGBTQ, Indigenous people, elders, those with lower socioeconomic status, people experiencing mental health challenges, and people with low health literacy or whose primary language is not English. This lack of representation limits the generalizability of research and may also significantly contribute to health disparities (Bonevski et al., 2014; Cohn et al., 2017). There are a variety of reasons for this under-representation which includes factors within diverse and vulnerable communities such as mistrust and fear around research but also factors within the research community such as lack of understanding and skills to engage these populations (Holzer et al., 2014; Erves et al., 2017).

Health Disparities

Health disparity is “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion”

U.S. Department of Health and Human Services, 2008

A key approach to address these issues is developing authentic partnerships with under-represented communities to help plan, conduct, and disseminate research. In doing so, research can be responsive to the needs and priorities of the population studied and methods can be sensitive to and respectful of the culture. Collaborative models of research, such as community-based participatory research (CBPR), have been shown to engage diverse patients, families, and communities in all stages of the research process, and thus, presents an effective approach to implement. Although CBPR has been used for many decades in social science research, it is a more recent development in health care research. Researchers need guidance to change the long-standing culture and beliefs in academic and research centers that may inhibit their ability to partner with patients, families, and community members.

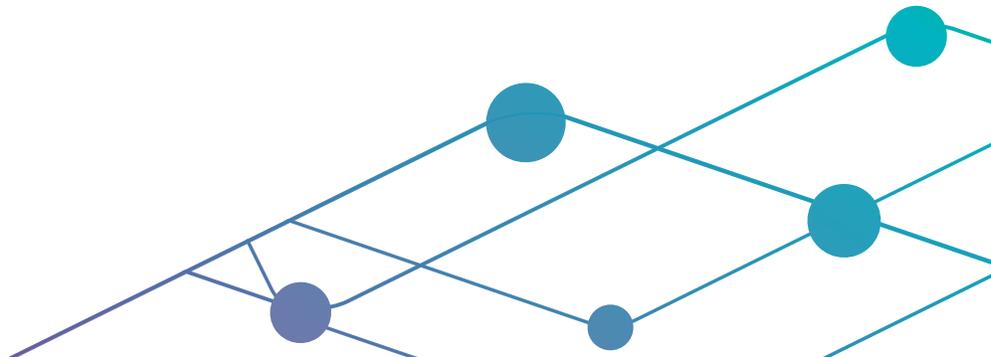
“Community-based Participatory Research (CBPR)...is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.”

W.K. Kellogg Community Health Scholars Program, 2001

Why haven't collaborative research models been adopted more quickly in health care research? There are a variety of reasons including the following:

- CBPR requires building trust and relationships, however, researchers may be unsure of how to initiate, develop, and maintain trust and relationships with diverse and vulnerable communities.
- The tendency to value academic expertise over lived experience and expertise can impede the cultural shift in research necessary to fully adopt CBPR.
- Internal organizational support for the necessary resources and infrastructure may be difficult to obtain.
- External funders may not provide incentives and support for collaborative research.
- Researchers lack understanding of practices to engage patient, family, and community partners; patient- and- family-centered approaches to health care; and other concepts critical to planning and conducting collaborative research.

The Strengthening Diversity in Research Partnerships: Knowledge to Action Guide was created to help any one interested in partnerships between researchers and diverse, underrepresented, and/or marginalized patient, family, and community partners (PFC partners). It serves to help build an understanding of the collaborative approach to research, learn strategies, access resources, and overcome challenges.



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 - An extensive literature review
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 - Interviews with experts who are involved in partnerships in health care research
 - Conference presentations
 - Site visits to three exemplary programs that authentically partner with diverse and vulnerable populations

Overview of the Knowledge to Action Guide

To achieve its aim of conducting patient-centered outcomes research, PCORI created the PCORI Engagement Rubric, a framework to offer concrete ways to operationalize engagement that incorporates patients and other stakeholders in all phases of research. The framework includes Principles of Engagement; definitions of stakeholder types; key considerations for planning, conducting, and disseminating engaged research; potential engagement activities; and examples of promising practices from PCORI-funded projects (Sheridan et al., 2017).

Building on the foundation of the Rubric, the Strengthening Diversity in Research Partnerships project team expanded the original Principles of Engagement to recognize and address the unique circumstances that

Principles of Engaging Diverse PFC Partners in Research

- Trust
- Reciprocal Relationships
- Honesty
- Transparency
- Cultural Competency
- Co-Learning
- Partnerships

(For full description of principles and strategies, see page 11)

arise when partnering with diverse and typically under-represented communities in research (see box, Principles of Engaging Diverse PFC Partners in Research). This expansion was based on the lessons learned about meaningfully and authentically engaging these communities from researchers, clinicians, and PFC partners participating in project activities. You can view the Principles with Strategies to Achieve on page 11.

The expanded principles provide the structure for this Guide. Each section of the Guide presents one of the seven principles and offers an Overview, Strategies and Insights, Stories from the Field, Top Tips, and Selected Resources. The intent is to offer practical guidance to facilitate engagement of diverse PFC partners so that research can be co-designed and co-implemented.

Appendices

Please see **Acknowledgements** for a listing of the individuals who shared their expertise. As part of this project, several resources that supplement this Guide were produced. These include an extensive **Annotated Bibliography** and an **Annotated List of Resources from the Field** that are included in the Appendices.

Additional Resources

Spotlight Videos were produced from site visits to exemplary organizations that partner with diverse individuals and communities and interviews with researchers and PFC partners at IPFCC's **8th International Conference on Patient- and Family-Centered Care: Promoting Health Equity and Reducing Disparities**. These are available on a special section of IPFCC's website, [Strengthening Diversity in Research Partnerships](#).

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Engaging Diverse Patient, Family, and Community Partners in Research

PRINCIPLES	STRATEGIES TO ACHIEVE PRINCIPLES
Trust	<ul style="list-style-type: none"> • Research is planned, conducted, and disseminated in a way that honors the trust developed with diverse patient, family, and community partners (PFC partners) and does not further marginalize and stigmatize a community. • Each person’s experience, insights, and voice are listened to, acknowledged, respected, and valued. • Commitment to building trust recognizes that cultural competency, an understanding of historical perspectives/experiences, and current realities of PFC partners, are paramount. • Researchers are accountable to the community being studied and share information in an ongoing and authentic manner.
Reciprocal Relationships	<ul style="list-style-type: none"> • Roles and decision-making authority of all research partners, including PFC partners, are clearly stated and, where possible, defined collaboratively. • Shared values are elicited and made explicit to all partners. • Relationships are reciprocal or bi-directional such that there is enriching benefit, investment, and/or improvement for the PFC partners and the community studied. • There are opportunities and processes in place for PFC partners to solicit research partners based on community-driven needs and community-identified research priorities.
Honesty	<ul style="list-style-type: none"> • PFC partners, other stakeholders, and researchers are committed to open honest communication with one another recognizing that this is essential to building trust, and ultimately, the success of the partnership. • Honest communication is jointly defined (i.e., what it is, how it is experienced, and how it can be achieved) by all partners.
Transparency	<ul style="list-style-type: none"> • Information is shared readily with all partners in the language, method, and manner that is most encouraging and supportive of engagement of PFC partners. • Goals and timelines for projects are clearly identified and agreed upon by all partners. • Major decisions are made inclusively, and whenever they cannot be, the reasons are clearly communicated to PFC partners.
Cultural Competency	<ul style="list-style-type: none"> • Cultural competency is viewed as more than a checklist and is thoughtfully woven into how all partners approach the project, how they work together, and how research is conducted. • Diversity is thought about in expansive terms, drawing from the pulse of the community, not traditional paradigms. • The diversity of the community selected for a study is reflected in the membership of the research team and in the PFC partners.
Co-Learning	<ul style="list-style-type: none"> • All partners are committed to learning from each other. • Opportunities exist in all stages of the research process so that all partners are able to continuously learn from each other • Efforts are focused on helping PFC partners understand the research process, rather than trying to turn PFC partners into researchers. • Researchers will learn about patient- and family-centered care and strategies to meaningfully engage PFC partners.
Partnerships	<ul style="list-style-type: none"> • Requests for time commitment of PFC partners are reasonable, respectful, and flexible. • PFC partners receive fair financial compensation for their participation. • Researchers meet diverse PFC partners “where they are” and honor their preferences for level and types of engagement. • Accessibility and inclusiveness are viewed broadly and accommodations are planned and implemented to support engagement. • Commitment and support of leadership in research and stakeholder organizations are viewed as essential to build and sustain engagement of PFC partners.

TRUST

Overview

Trust undoubtedly emerged as the most critical principle of engagement necessary to strengthen partnerships with diverse and underserved communities in research. Without trust it will be impossible to collaborate in a meaningful and authentic way. Notably, the relationship between the principle of trust and all of the other principles of engagement is mutual; you cannot achieve one without the other. Through all of the information gathered for this Guide from all types of partners, the most critical value of trust that emerged is that it must be built, earned, and consistently nurtured over time.

For individuals who are from diverse, vulnerable, and marginalized communities, trust of research and researchers is a complex concept with different, nuanced meanings influenced by culture, experiences, and history. For many, distrust of research or outsiders is deeply ingrained, regardless of the value of a proposed project to their community. Experiences fostering mistrust could have occurred to the individual, family, or the larger community within recent memory or in prior decades. Mistrust of research is influenced by a variety of factors including:

- Medical experimentation or abuse within their community
- Sustained disparities in health and other basic needs (such as food, housing, employment)
- Limited access to health care
- Negative interactions with the health care system
- Lack of culturally or linguistically appropriate care
- Lack of information about research
- Stigma, stereotypes, myths, and misperceptions about diagnoses and diseases
- Lack of dissemination of findings to the community after a study is completed

The complexity of factors affecting trust formation makes communication and relationship building both challenging and absolutely critical. The information from the literature and from those who participated in project activities indicated that to truly engage in partnerships with diverse PFC partners, a commitment to building trust that is culturally competent and grounded in understanding of both current realities and historical perspectives/experiences is essential. Many emphasized that the time necessary to engage in honest conversations, storytelling, listening, and other activities that facilitate trust has to be proactively planned into project timelines.

“It is imperative that the process never ends. Seeking to understand, prioritizing, and partnering with the community is an ongoing process.”

Pearl McElfish
Director, Office of
Community Health
and Research
Vice Chancellor,
UAMS Northwest

Strategies & Insights

- **Research is planned, conducted, and disseminated in a way that honors the trust developed with diverse patient, family, and community partners (PFC partners) and does not further marginalize and stigmatize a community.**
 - Key informants indicated that this strategy is not just about planning and conducting research that does not further marginalize or stigmatize. In order to develop and strengthen partnerships with diverse PFC partners, trust must be built to achieve these outcomes in a meaningful way for communities and researchers alike. Honoring the trust that is built, in turn, involves consistently employing all the principles of engagement to co-design, co-implementation, and co-dissemination of research.
- **Each person's experience, insights, and voice are listened to, acknowledged, respected, and valued.**
 - Many shared that building trust often begins with simple principles of human engagement, such as communication and creating a sense of openness.
 - All partners are made to feel welcome and that they belong.
 - Time is set aside for mutual sharing and for researchers and PFC partners to engage in storytelling to promote connections, shared values, and understanding.
- **Commitment to building trust recognizes that cultural competency, an understanding of historical perspectives/experiences, and current realities of PFC partners, are paramount.**
 - Insights focused on valuing lived experience equally with professional expertise. Such equity requires time and infrastructure to learn about culture and history, build an understanding of each other, and develop relationships. Commitment to nurturing trust requires real human interaction, flexibility, and openness.
- **Researchers are accountable to the community being studied and share information in an ongoing and authentic manner.**
 - Accountability was universally emphasized as an important strategy to both developing and maintaining trust. The need for ongoing communication and information sharing was highlighted as particularly important as many diverse partners expressed that their communities felt used when researchers came to obtain something (e.g., data) and did not return to present findings.
 - Many specifically noted that the years it takes to conduct a research study make regular updates or "check-ins" with the community critical. Without these, trust is eroded as lack of communication can easily be misinterpreted in the context of past negative experiences with research. Consistent and ongoing communication and information sharing (in simple forms such as a call, Facebook post, or potluck luncheon or more in depth forms such as community meetings), goes a long way to maintaining trust, commitment, and engagement.

Stories from the Field

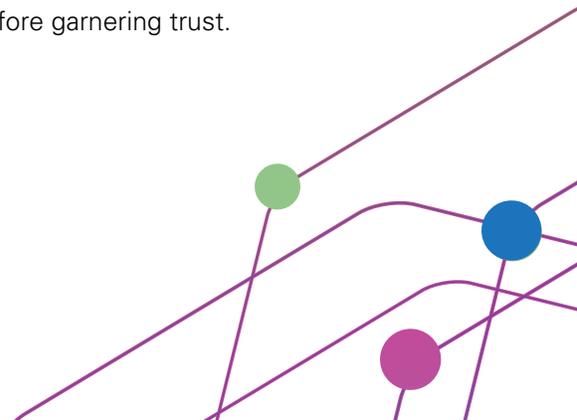
University of Chicago Medicine, Center for Community Health and Vitality

Doriane Miller, MD, Associate Professor of Medicine and Director of the Center for Community Health and Vitality at the University of Chicago Medicine discussed the challenge of including populations that have not been involved in research, indicating that difficulty may arise in connecting with that community in a way that is genuine especially when there is a history of mistrust. In her work with people who live and work on the South Side of Chicago, she noted that many cite things like the Tuskegee Study as an influence. Although they may not have direct knowledge of it, they do have ancestral knowledge because many family members came from the south and they were very aware of this experiment.

Dr. Miller also touched on a misconception held by many academics and researchers that including PFC partners in research “may muddy the waters and make research more difficult.” Dr. Miller offered a suggestion for overcoming this by emphasizing the importance of not just sending representatives to build relationships with communities, but instead ensuring principal investigators (PIs) are educated in principles of patient engagement. PIs can then go directly to the community and talk about who they are, why they are involved in research, and what they think are the benefits for the community. Dr. Miller acknowledged that in so doing and in seeking to understand the needs and preferences of communities, academics and researchers often learn that community priorities may not line up with their own plan. She urged that researchers learn to work within that space and offered that “asking better questions and getting better answers” comes from open communication, authenticity, and trust building.

Northern Arizona University, Center for Health Equity Research

Emery Eaves, PhD, Assistant Professor of Anthropology shared her overall experience in working with Native Americans and other diverse partners in research. She expressed the value she has been able to add to her research in the past because she grew up in the area, leading to an ability to establish relationships with community partners based on her deeper understanding of beliefs and traditions. Dr. Eaves indicated that one of the reasons she believes people are engaging in the community-driven approach to INSPIRE (Involving Native Stakeholders in Pain Research Efforts) is because the co-lead is a well-respected member of a local Native American community, therefore garnering trust.



University of Arkansas for Medical Science, Fay Boozman College of Public Health

Keneshia Bryant-Moore, PhD, RN, FNP-BC, Associate Professor at the Department of Health Behavior and Health Education, shared that as someone who is originally not from Arkansas, she had to work hard to get to know the people who know the community well. She noted that this takes time and patience, but is critical to relationship and trust building. Dr. Bryant-Moore recounted that at one time she inadvertently chose the wrong person in the community to collaborate with and it created chaos and distrust in the community. She remarked, “you can’t just take someone’s word for it that they are leaders in the community, you have to observe and engage in the community too.”

University of Arkansas for Medical Sciences Northwest

At the University of Arkansas for Medical Sciences Northwest they focus on health disparities. In looking at where the greatest needs were, it was apparent that the Marshallese and Hispanic populations showed the highest disparities. The Marshallese had the greatest needs so they began with that population. Researchers, staff, and Marshallese partners indicated that to gain the trust of the Marshallese, one must know the community, language, culture, and people. Before beginning any research studies, researchers from UAMS Northwest spent over one and a half years building relationships in the community and gaining a deep understanding of the culture and the needs of the Marshallese. They used a variety of methods including surveys, focus groups, and qualitative interviews that the researchers conducted in partnership with Marshallese. These were done in the Marshallese language.



Marshallese Staff at UAMS Northwest

Beyond formal methods of getting to know a community, they also discovered that it was important to build more informal relationships with Marshallese people. A representative of a community organization shared that the most valuable way to gain trust of the Marshallese has been for researchers to “show up and be there” in the community including at events that are important to the community, such as Constitution Day. Presence in the community is interpreted to mean that “you care,” and does a lot to build trust and relationships.

“We want to be connected to the community so we build that trust. When we go back and work with them, they know that we’re not just there to get data. It’s very important to give them the data.”

Morda Netwon, Project Coordinator, UAMS Northwest

PRIDEnet

Carolyn Hunt, MPA, Community Engagement Director at PRIDEnet brought up the crucial role that timely dissemination of research findings plays in keeping diverse partners engaged and protecting the trust built with these partners. PRIDEnet is a participant-powered research network of sex and gender minorities. She noted that for the LGBTQ community, sharing results and ensuring that they are used for the benefit of the community is of utmost concern and directly plays into community trust. As such, she shared that dissemination is a next step for their project and the PRIDEnet advisory group has begun to take steps to create requirements related to dissemination. For example, when a submission is made to apply to use data that PRIDEnet collects, a plan for communicating progress and findings is required. This guidance recognizes that dissemination is not “nice to do” but essential. Ms. Hunt also addressed the need to consider all of the factors that could affect accessible and plain language communication of research findings, such as developing summaries that are brief and smart but not full of jargon, and getting them into the hands of the appropriate community-based organizations.



PRIDEnet Community Listening Session

TOP TIPS

- Honor trust that is built by actively and consistently engaging diverse PFC partners in all stages of the research process.
- Be open to “humanism in research.” Listen, communicate, be vulnerable, and tell stories to build relationships and reach shared understanding and goals.
- Accountability to the community should be achieved across the spectrum—from “showing up and being present” in a community to regular updates and everything in between.

Selected Resources

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Selected Resources *continued*

Khodyakov, D., Mikesell, L., & Bromley, E. (2017). Trust and the ethical conduct of community-engaged research. *European Journal for Person-Centered Healthcare*, 5(4), 522–526. doi:10.5750/ejpch.v5i4.1263

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Program Websites

Center for Health Equity Research at Northern Arizona University at <http://cher.nau.edu/>

PRIDEnet Blog at <https://medium.com/thepridestudy>

UAMS Fay W. Boozman College of Public Health at <https://publichealth.uams.edu/research/current-research-projects/>

UAMS Northwest Campus – Office of Community Health and Research at <https://northwestcampus.uams.edu/chr/>

Additional Resources

See an **Annotated Bibliography** and an **Annotated List of Resources from the Field** in the Appendices. To view **Spotlight Videos** featuring programs, researchers, and PFC partners, visit the special section of IPFCC's website, [Strengthening Diversity in Research Partnerships](#).

RECIPROCAL RELATIONSHIPS

Overview

In the thesaurus, the closest synonym to reciprocal is mutual.

This is central to patient- and family-centered care (PFCC), an approach to care and a model for transforming health care systems, that is grounded in mutually beneficial partnerships. Similarly, all forms of community-based participatory research are grounded in mutually beneficial or reciprocal relationships. Thus, PFCC and community-based participatory research have directly evolved as approaches that can assist all partners in building bridges across the chasm between diverse patients/families/communities and providers/researchers to ultimately support better health and reduce health disparities. Through the information gathered for this Guide, four critical values of reciprocal relationships emerged: equality, respect, shared priorities and goals, and “give and take.”

Developing reciprocal relationships in research requires recognition and respect for lived experience as equal to professional experience. True reciprocity is not likely to happen if one party does not believe in the other’s contributions. This principle may require investments of time and resources not always accounted for in traditional research plans.

Researchers and PFC partners noted several benefits, such as:

- Networking, making connections, and developing relationships
- Learning about surface and deep cultures within a community
- Co-learning about research and a community
- Building of reputation and credibility of researchers and academic institutions within a community
- Redressing inequalities in health care
- Identification of common and shared values to inform research
- Reaching compromises as necessary that are acceptable to all

Reciprocity is not formulaic, nor can it be established in one meeting. Instead, informants emphasized the need for ongoing exchange to develop and maintain equal, working reciprocal relationships.

“The gift that was revealed to me was ‘help these people.’ Be the light at the end of the tunnel. Be the hope that is there. I’m here to help people by any means possible.”

Marilyn Perez-Aviles
Lived Experience
Researcher
Chicago Health
Disparities Center
Illinois Institute of
Technology

Strategies & Insights

- **Roles and decision-making authority of all research partners, including PFC partners, are clearly stated and, where possible, defined collaboratively.**
 - Informants stressed the critical need to have more than one meeting, preferably face to face, in which roles are clearly discussed, conversation is transparent, and the general research process is explained. These meetings place all partners on the same page and helps everyone to negotiate as much as possible the roles, decision-making, and research process.
 - This strategy was identified as important to addressing any power differences and creating equal relationships. It was noted that if discussions are not held in the open between all partners about roles and expectations, then it is possible that past experiences, stereotypes, and other negative factors may prevent movement of all partners toward reciprocity grounded in mutuality, respect, and equality.
 - Some noted that where roles already exist, there may be limited ability to collaboratively define roles. However, whenever this occurs, roles do need to be explicitly stated. In some communities the need for collaborative definition of roles is a crucial process to develop trust and reciprocity. Every opportunity to define roles together should be taken.
- **Shared values are elicited and made explicit to all partners.**
 - Transparent and honest conversations were identified as the key to making this principle a reality.
 - This strategy is important to redressing inequities in past or current researcher/diverse PFC partner relationships because it provides for sharing, story telling, connection, and a humanistic approach. Sharing was highlighted as critical to the give and take necessary for basic communication and to develop overarching reciprocal relationships. It leads to an understanding of each other and the recognition that all can contribute equally.
 - Many informants noted the need to explicitly “ask” PFC partners about their preferred goals for research. While this conversation can begin in the traditional way of a researcher coming to the community with questions or ideas, the majority indicated that to make strides in meaningful engagement of PFC partners, discussions of research topics and questions need to dive deeper into the perspectives and priorities of all. This takes time and often requires several meetings. Additionally, many noted that this may be a situation in which flexibility is important, as once asked, the priorities and goals shared may be completely different than the original plan and thus require adjustments.

- **Relationships are reciprocal or bi-directional such that there is enriching benefit, investment, and/or improvement for the PFC partners and the community studied.**
 - Overwhelmingly, informants discussed how critical it is when conducting research with diverse and vulnerable communities to carefully consider how the research will ultimately serve the community. PFC partners and researchers reported that in the past many marginalized communities would be seen solely as research subjects and once research was completed, the relationship ended and researchers were not seen again. If their communities agree to participate in research, the PFC partners want researchers to come back and work with them to understand the significance of findings to the community so that they and others can use the findings to improve their community.
 - Some suggested using research methodology that allows all study participants to receive the intervention (e.g., stepped-wedge design).
 - PFC partners from many of the programs that informed this Guide discussed the importance of being able to build knowledge and skills that are necessary to engage effectively with researchers but also those that help them develop skills in areas that will benefit them beyond the partnership, including leadership and communication skills.

- **There are opportunities and processes in place for PFC partners to solicit research partners based on community-driven needs and community-identified research priorities.**
 - This strategy recognizes that some diverse PFC partners can become so engaged in research that they actively identify their own community-identified research questions and in turn solicit research partners. There are a growing number of models of “studios” in which researchers bring ideas to a group of PFC partners for feedback. Some programs are expanding the “studio” concept to establish them as forums for PFC partners to help researchers identify research questions and to continue to partner with researchers continuously over time in conducting the research.
 - This strategy involves meeting diverse PFC partners “where they are.” It also heralds the wisdom and power of lived experience and the resilience of diverse communities to not only bring about change in their own health and their community, but also bring about change in how research is designed and conducted.

“It’s a daily process of us going back to the community and fully explaining what is going on so they are fully informed. It’s our duty to make sure they are fully involved in the process.”

Lisa Smith, MBA, Director of Programs and Administration
Office of Community Health and Research, UAMS, Northwest

Stories from the Field

Leonard Schanfield Research Institute at CJE SeniorLife

Amy Eisenstein, PhD, the Director of the Leonard Schanfield Research Institute at CJE SeniorLife in Chicago, IL shared that they are having discussions over the sustainability of the Bureau of Sages, a research advisory board composed of elders, researchers, and outside clinicians. The amount of turnover in long-term care staff who serve as key contacts has affected the functioning of the Bureau



Courtesy of CJE SeniorLife

of Sages. However, the Sages want to continue their efforts. She noted that as a result of their work, the Sages have identified their own research priorities and agenda and have been soliciting researchers to partner with them.

Wisconsin Network for Research Support (WINRS), UW-Madison School of Nursing

Gay Thomas, MA, Director of Stakeholder Engagement and Betty Kaiser, PhD, RN, Director of Stakeholder Training at the Wisconsin Network for Research Support (WINRS) UW-Madison School of Nursing reported that their initial plan was to gradually transfer responsibility for running the Community Advisors on Research Design and Strategies (CARDS®) meetings to CARDS members. However, this has not happened for several reasons. When WINRS hired someone to do a qualitative study of CARDS, they learned that the members are clear that they like functioning exactly the way they are. They are compensated and treated fairly and are fulfilled by the level of engagement. The members of CARDS value their relationship with the meeting facilitators and feel that the whole group is a type of “family.” They feel respected for who they are and the experience and expertise they bring to the table.

Northern Arizona University, Center for Health Equity Research

Nicolette Teufel-Shone, PhD, Associate Director of the Northern Arizona University Center for Health Equity Research has been involved with a National Institutes of Health-funded group connected to environmental health in writing guidelines for forming a Community Advisory Board (CAB). Currently the work has focused on Native American communities but the intent is to test in non-Native communities as well. Her contribution to the writing of guidelines has been based

on lessons learned and a perspective shaped by her years of experience working with Native American communities. In particular, she finds herself influenced by the question whether researchers may be too heavy handed in how they guide CAB formation and function versus inviting communities to establish CABs on their own and determine how it will function.

One of the most rewarding efforts related to CABs came within a project funded by the National Institutes of Health and the Substance Abuse and Mental Health Services Administration. The project was focused on building a positive environment for youth in the community. Community navigators truly drove the project, engaged committed community members, and ensured that CAB members stayed active and committed. This effort in turn fostered a different sort of engagement by the CAB because the community investigators had recruited people from a variety of sectors of the community deeply connected to youth. Teufel-Shone noted that the work of this CAB and the retention of its members was in large part due to the freedom given to the CAB to form and conduct business in a way that respected and promoted the local culture.

PRIDENet

Carolyn Hunt, MPA, Community Engagement Director of PRIDENet, a participant-powered research network of sexual and gender minorities (SGM) indicated that PRIDENet works to establish relationships through demonstrating their long-term commitment with each individual patient-powered research network participant as well as with the 40 community partner organizations. As Ms. Hunt described, the SGM community needs love, support, and trusting relationships, so PRIDENet takes the time to provide direct and personal feedback and interact with individuals who reach out to them. Ms. Hunt reflected that the most disenfranchised communities need programs built that manifest love and support in messaging and every interaction. In particular, Ms. Hunt noted that they are committed to ensuring that PRIDENet is furthering the mission of the individual partners and that they consistently put forth their best effort. She expressed that the organizational partners requested support from PRIDENet including being provided resources, toolkits, prompts, and tailored plans to help their constituents.



PRIDENet Community Partners

University of Arkansas for Medical Sciences Northwest, Office of Community Health and Research

Dr. Peter Kohler, recently retired vice chancellor of UAMS Northwest and Dr. Pearl McElfish, director of the Office of Community Health and Research, co-director of the Center for Pacific Islander Health and associate vice chancellor of UAMS Northwest shared some of the strategies that have been critical to their efforts and success such as hiring Marshallese community members as staff, ensuring diversity of staff, conducting a thorough needs assessment jointly with the community, taking time to



Courtesy of UAMS Northwest

build relationships and trust, bi-directional continuous learning, and dissemination of findings to the community. Discussions also focused on the importance of flexibility that is helpful when balancing the needs of the community with that of science. For instance, during one study, they identified the immediate need for accessible and affordable health care for the Marshallese. Due to the Marshallese special status as “non-immigrant” they do not have access to supports and services including Medicaid, Medicare, cash assistance, and food stamps typically provided to other low-income residents of Arkansas. While outside of the scope of the study, UAMS Northwest responded by setting up free community clinics for the Marshallese.

Chicago Health Disparities Center at the Illinois Institute of Technology

The Chicago Health Disparities Center at the Illinois Institute of Technology (IIT) is committed to reducing physical health disparities for racial and ethnic minorities with mental illness. Individuals with lived experience collaborate with researchers on a variety of projects. Roles for individuals with lived experience include Leadership Advisory Board members, peer navigators, research assistants, and research leaders.



Leadership Advisory Board Meeting

Many not only shared a sense of accomplishment in themselves and for their communities, but also a deep appreciation of the process of the training they received, their development as researchers, and their involvement in research. In fact, many noted that the impacts of the supportive process of training and research at IIT helped them into recovery or helps to maintain their recovery. Several indicated that the ability to help others assisted them in making sense of their life experience in invaluable ways. The majority of interviewees shared that their work with IIT has helped them find or get reacquainted with their skills, worth, and value. Many stated that leadership roles involving the creation of research questions of importance to their community, curriculum development, presentation of materials and results, and many other activities enable them to recognize the importance and value of their story and experience to the research and beyond.

TOP TIPS

- Consistent, face-to-face meetings with honest, transparent, and informative discussion build mutuality and equality in a research partnership so as to overcome misperceptions, stereotypes, and past hurts/abuses.
- Consider and plan for how the research will benefit the community in a thoughtful, mutual, and ongoing basis with give and take with the community.
- Ask, listen to, and talk with PFC partners about their preferred goals for research.

Selected Resources

- Cheney, A., Haynes, T., Olson, M., Cottoms, N., Bryant, K., Reaves, C., . . . Sullivan, G. (2018). Using deliberative and qualitative methods to mobilize community around the mental health needs of rural African Americans. *Health Systems and Reform, 4*(1), 8-18. doi:10.1080/23288604.2017.1404180
- Corrigan, P., Pickett, S., Kraus, D., Burks, R., & Schmidt, A. (2015). Community-based participatory research examining the health care needs of African Americans who are homeless with mental illness. *Journal of Health Care for the Poor and Underserved, 26*(1), 119-133. doi:10.1353/hpu.2015.0018

Selected Resources *continued*

Examining Community-Institutional Partnerships for Prevention Research Group. (2006). *Developing and sustaining community-based participatory research partnerships: A skill-building curriculum*. Retrieved from <http://depts.washington.edu/ccph/cbpr/index.php>

Ferre, C. D., Jones, L., Norris, K. C., & Rowley, D. L. (2010). The Healthy African American Families (HAAF) Project: From community-based participatory research to community-partnered participatory research. *Ethnicity & Disease, 20*(1 Suppl 2), S2-1-8.

McElfish, P. A., Moore, R., Laelan, M., & Ayers, B. L. (2018). Using CBPR to address health disparities with the Marshallese community in Arkansas. *Annals of Human Biology, 45*(3), 264-271. doi:10.1080/03014460.2018.1461927

Program Websites

Bureau of Sages at Leonard Schanfield Research Institute at CJE Senior Life at www.cje.net/research-education/bureau-sages

Center for Health Equity Research at Northern Arizona University at <http://cher.nau.edu/>

Chicago Health Disparities Center at Illinois Institute of Technology at www.chicagohealthdisparities.org

PRIDEnet Blog at <https://medium.com/thepridestudy>

UAMS Northwest Campus – Community Health and Research at <https://northwestcampus.uams.edu/chr/>

WINRS (Wisconsin Network for Research Support) at <https://winrs.nursing.wisc.edu/>

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HONESTY

Overview

In life, honesty is often referred to as a “golden rule.”

In research, it is elevated to a similar “rule” status in that it is part of a code of ethics. Honesty requires truthfully reporting data, results, methods, procedures, and publication status. Thus, it can be said that an honest researcher is one who values the scientific record. But the principle of honesty takes on an additional meaning when researchers invite PFC partners into all stages of the research process.

PFC partners and researchers working with them describe the principle of honesty as foundational to building trust, relationships, and ultimately, authentic, productive partnerships. They report that honesty and transparency are principles that are inextricably linked, but are also distinct and require a different set of actions. Researchers talked about the importance of acknowledging their own discomfort and history as it relates to the research partnerships and the need to be open to their vulnerabilities. Perhaps most notable was the need to “be real” and authentic which may require stepping out of a “researcher persona” and being able to see the paradigms and biases they may hold.

While these concepts do not focus on protecting the scientific record, they add to that definition by valuing honesty in communication and require presenting oneself honestly. For diverse PFC partners who may hold negative beliefs or feelings given their communities’ past experiences with research, one can readily understand that seeing a researcher adhere to the scientific record alone may not be “enough” for them to believe that honesty is being held as a core value. Those who successfully engage diverse and/or marginalized PFC partners in participatory research make the effort to be honest in all communication and interactions.

Honesty is perhaps the most aspirational of the principles for engaging diverse PFC partners in research. Researchers, staff, and PFC partners with whom we spoke as part of this project emphatically identified honesty as a foundational principle. However, it was difficult for them to describe specific strategies that operationalize this broader concept of honesty in research partnerships.

“You have to be real. For people where there is a legacy, historically and ongoing, of distrust and mistrust of people in positions of power, they have to feel that you are interested. You have to tap into their lived experience and that may mean finding the connection to your experience. People can see when you genuinely care.”

Crystal Cené, MD,
MPH, FAHA
Associate Professor,
Division of General
Internal Medicine,
UNC School of Medicine

Strategies & Insights

- **PFC partners, other stakeholders, and researchers are committed to open honest communication with one another recognizing that this is essential to building trust, and ultimately, the success of the partnership.**
 - Honest communication is active and does not accept silence or omission even if researchers or PFC partners do not directly ask for specific information. All must be committed to sharing information that is important to the process.
 - Being real and authentic may require vulnerability that is a bit unfamiliar to researchers and different from the traditional scientific code of ethics for honesty in research. Therefore, it is helpful if all make a commitment to be open in communication and perspective and strive to put it into practice.
- **Honest communication is jointly defined (i.e., what it is, how it is experienced, and how it can be achieved) by all partners.**
 - Jointly defining what constitutes honest communication, as well as how it may be experienced and achieved, prevents assumptions about honest communication and fosters trust, partnerships, and the research project.
 - Jointly defining honest communication can facilitate open discussion, particularly important to acknowledging sensitive topics and historical missteps with diverse PFC partners and research.
 - Jointly defining honest communication enables all to thoughtfully reflect about themselves as well as their role in the research partnership.



Stories from the Field

Wisconsin Network for Research Support (WINRS), UW-Madison School of Nursing

Born out of the persistent problem with recruiting diverse participants to clinical trials, WINRS was developed to bridge the gap between the clinical trial world and the community. Using principles of community-based participatory research, WINRS created otherwise non-existent methods for researchers to engage with patients. In a 2017 article, “The Power of The Personal: Breaking Down Stereotypes and Building Human Connections,” Gay Thomas, Betty Kaiser, and Kaitlin Svabek shared their innovative process called, Community Advisors on Research Design and Strategies (CARDS®). CARDS® provides a forum for researchers to connect with and learn from community advisors.

Two methods are used to build connections between the researchers and community advisors:

- Open with a carefully constructed question that everyone has to answer; and
- Provide time in the meeting for the researcher to explain the personal motivation behind their research.

Both of these strategies help the researchers and community advisors form a relationship and build an understanding of each other. But Thomas and her colleagues note that these methods have to be well thought through and researchers often need some preparation to be able to respond from their personal, not professional constructs. Crafting an appropriate opening question is challenging—the intent is to have people share stories that “engender positive



Courtesy of WINRS

emotions and reinforce human connections.” They have learned through trial and error to avoid questions that yield stale, boring responses or bring up negative memories. Asking researchers to be candid about their motivation for the study may be difficult. Researchers may want to talk about the scientific need for the research but community members appreciate when they hear the more personal and honest reason. Their willingness to participate in helping the researcher in the study is greatly improved by understanding why a particular topic is personally important to the researcher.

“I love the opening questions. They help us accept the researcher. When we share life experiences, we see each other as human.”

Community Advisor, Thomas, et al., 2017

California Center of Excellence for Behavioral Health at UCLA and Healthy African American Families Phase II

Dr. Kenneth B. Wells, Director of the Center for Health Services and Society, Semel Institute for Neuroscience and Health Behavior and Co-Director of the California Center of Excellence for Behavioral Health at UCLA spoke in an interview about the partnership between UCLA and the Healthy African American Families Phase II (HAAFII), a large community agency. Since their partnership began in 2003, they have engaged in a number of research projects. The concepts that they follow include developing trust, handling conflict, and addressing the issue of historical distrust within the community. He shared that it takes an intentional approach especially in his situation as a white male researcher. Dr. Wells reflected on some of the key aspects of how he has been able to engage with diverse partners in the area of behavioral health. He noted that it is important to be aware of his limitations and how he can partner effectively, as well as maintaining humility, recognizing that he is going to make mistakes. He values his HAAFII partners who are honest and help him course correct when needed.

“In one community during our data analysis and development of a joint-authored paper for publication, I was suddenly asked why I was doing this kind of work, ‘what are you getting by working with us anyway?’...Although initially the question made me uncomfortable, it also opened up a deeper honesty and led to all of us sharing perspectives and recommitment.”

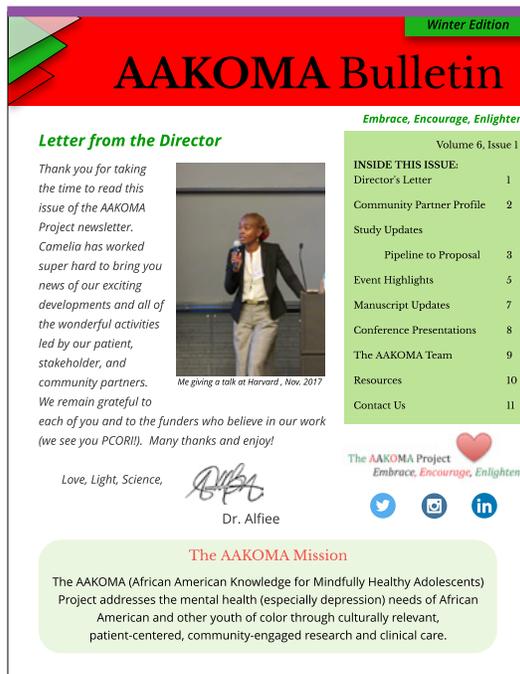
Wallerstein & Duran, 2006

Research Division of the Department of Psychiatry at Georgetown University Medical Center

When asked about the principles of engagement most important to her work in collaborating with youth and families in behavioral health research, Dr. Alfiee Breland-Noble, Associate Professor of Psychiatry at the Research Division of the Department of Psychiatry at Georgetown University Medical Center and the Director of the African American Knowledge Optimized for Mindfully Health Adolescents Project (AAKOMA), offered one word—authenticity. She shared that in her experience and opinion, this is the most important element to meaningful engagement of diverse and unrepresented partners in research. She emphasized the importance of being oneself; meaning as

a researcher and mental health professional, she brings all of herself personally and professionally to the table, not creating boundaries or ignoring her own experience and community. Dr. Breland-Noble stressed the importance of this type of humanity in research and the health care system. It is the opposite of how providers have been trained, but it is what they must now move to in order to connect with people. This is particularly true when working with diverse partners who have a serious distrust of research.

When asked how she has engaged African American youth struggling with mental health conditions and trauma in research, Dr. Breland-Noble recounted a variety of strategies stemming from authenticity. She highlighted principles such as listening (and being quiet), valuing everyone’s contribution (and believing everyone has a contribution), being willing to share personal connections, making youth feel important, and being willing to admit to youth when you don’t know something.



Georgetown AAKOMA Bulletin

TOP TIPS

- Be honest and open in your communication and interactions.
- Take time to self reflect about your paradigms and biases.
- Remain willing to share your authentic self with others.
- Have conversations with partners about what honesty in research means.

Selected Resources

Thomas, G. R., Kaiser, B. L., & Svabeck, K. (2017). The power of the personal: Breaking down stereotypes and building human connections. *Narrative Inquiry in Bioethics*, 7(1), 27-30. doi:10.1353/nib.2017.0010

Thomas, G., & Kaiser, B. (2018). *Patient advisor toolkit 1: Orientation for patient advisory committees (PAT-1)*. Madison, WI: Wisconsin Network for Research Support, University of Wisconsin – School of Nursing, and Health Innovation Program. Available at <https://www.hipxchange.org/PAT-1>

Wallerstein, N., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice*, 7(3), 312-323.

Program Websites

AAKOMA Project (African American Knowledge Optimized for Mindfully Health Adolescents) at www.aakomaproject.org/

California Center of Excellence for Behavioral Health at UCLA at <http://hss.semel.ucla.edu/cce/>

HAAFII (Healthy African American Families Phase II) at www.haafii.org

Wisconsin Network for Research Support at UW-Madison School of Nursing at <https://winrs.nursing.wisc.edu/>

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TRANSPARENCY

Overview

Transparency in research quite simply means conducting research in a way that is easy for others to see and understand all decisions, actions, processes, and outcomes of the research. While similar to the principle of honesty, the principle of transparency is in fact distinct. Diverse PFC partners report that while the two principles are inextricably linked, transparency requires different efforts and strategies. In this project, three critical values of transparency in research emerged—openness, communication, and accountability.

Transparency in collaborative models of research involves making the research visible and available to all stakeholders. Every detail will not require transparency but consensus about what needs to be shared should be built together with PFC partners. Important planning and decisions around research priorities and questions, project design and methods, study materials, analysis, and dissemination activities deserve transparency. Shared decision-making about what needs to be transparent naturally fits as part of the relationship-building process with PFC partners. These discussions may take longer and relies on researchers and PFC partners being willing to be open and flexible. PFC partners indicate that transparency addresses common fears and concerns they may have such as:

- Feeling taken advantage of
- Feeling that they are giving more than they are receiving
- Mistrust of motivations of researchers
- Perceived lack of investment in the community
- Misunderstanding between “sides” (i.e., researchers and community)
- Perceived researcher insensitivity to the community’s past experience with research

“We have a lot of conversations like ‘what is the institutional review process?’ We are able to be open about the questions we have about the research process. I can trust the process when there is an element of transparency.”

Ashley Scott
Member, Community-
Based Participatory
Research Team
Chicago Health
Disparities Center,
Illinois Institute of
Technology

Strategies & Insights

- **Information is shared readily with all partners in the language, method, and manner that are most encouraging and supportive of engagement of PFC partners.**
 - Researchers and PFC partners shared that experience has shown transparency and information sharing lead directly to honesty and demonstrate integrity of the researchers and the study. Given the negative past experiences of many diverse communities with research, transparent information sharing was noted as one of the most critical aspects of developing trust and authentic partnerships.
 - Attention to how information is shared as well as received is of particular importance to transparency, but also to demonstrate integrity, investment in the relationship, and authenticity. Not only did researchers and PFC partners note that this requires asking questions and listening, but they also reported that researchers need to be culturally responsive and make appropriate accommodations to meet specific needs of diverse PFC partners.
- **Goals and timelines for projects are clearly identified and agreed upon by all partners.**
 - Researchers and PFC partners indicated that transparency in and about all aspects of the design, planning, and conduct of research is directly linked to the meaningfulness of that research for diverse communities. Many noted that lack of transparency in these aspects also affects willingness of PFC partners to engage and build trust with researchers.
 - In many diverse communities concepts of time are informed by cultural norms just as the timelines in research projects are informed by institutional culture, including funding parameters and scientific paradigms. The importance of researchers and PFC partners explicitly discussing perceptions of time helps build a clear understanding.
 - Discussing timelines and goals was noted as critical so that expectations are clear to all and any necessary flexibility can be built in. Researchers noted that this is challenging as many funders and institutions may not be receptive. But they universally noted that staying flexible and open to changes suggested by PFC partners improved their projects and supported the development of trust.
- **Major decisions are made inclusively, and whenever they cannot be, the reasons are clearly communicated to PFC partners.**
 - PFC partners emphasized the role of expectations in affecting their ongoing participation. Joint planning for how decisions will be made was noted as a strategy to initiate and foster engagement and establish shared expectations about decision-making. Similarly, continued transparent communication about decisions keeps expectations intact and helps dispel feelings of mistrust.

Stories from the Field



Excerpt from COPE's 2016 Annual Report

Community Outreach and Patient Empowerment (COPE)

COPE is a formal collaboration between Brigham and Women's Hospital, the Navajo Nation Community Health Representative Program, Navajo Area Indian Health Service, and Partners In Health. Olivia Muskett, Community Outreach Manager, shared about her own need for transparency as a member of the Navajo Nation and as a professional. She shared that prior to working with COPE, she was a community health worker. She reflected that she did not initially trust COPE. She perceived that they wanted something from the Navajo Nation and would in turn be like many others from the outside—pushing their own agenda and leaving when it was fulfilled regardless of community need. However, as more information was shared (with the community and through training for Ms. Muskett's professional role), questions were

asked which led directly to more transparent conversations between Ms. Muskett, community health workers, the Navajo community, and COPE. Ms. Muskett shared that this helped develop trust and willingness for the community to engage.

Ms. Muskett and COPE staff continue to advocate and encourage the community to ask many questions. They feel it is critical that the engagement of diverse partners not be viewed as a one-time meeting, but rather, an iterative process focused on listening and relationship building. Additionally, COPE is always willing to have open and honest discussions about the history, research, goals, and concerns of the community. Bolstered by these open conversations, COPE worked with the community to create a Journey Map to approach the idea of doing research. This map focused on the strength and wisdom of the Navajo partners and led to contemplating how best to incorporate these.

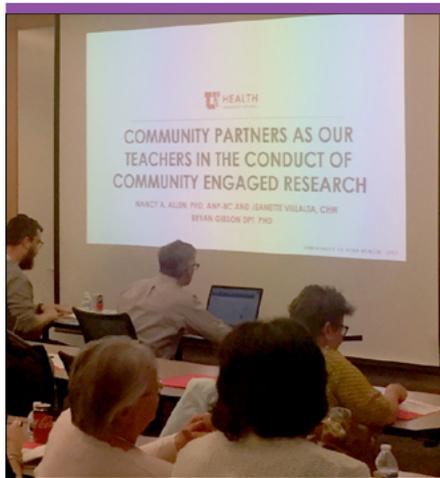
PRIDENet

PRIDENet, based at the University of California San Francisco, is a network of organizations and individuals who are committed to engaging LGBTQ people in planning, conducting, and disseminating health research. Carolyn Hunt, MPA, Community Engagement Director of PRIDENet, shared of one of the most unique aspects of PRIDENet—the technology. It was chosen as a means to engage the LGBTQ community given the issues within this community related to comfort with being publicly out, the urban/rural divide, accessibility, privacy, and open access to information important to the LGBTQ community as well as their health and well-being. The user-friendly technology provides a safe way to encourage and facilitate engagement both as study participants and research advisors while also protecting from possible stigma and abuse.

Overall, Ms. Hunt noted that technology-involved research is a double edge sword. In theory, access to technology platforms for research and engagement will increase participation but an enormous barrier looms large in that there is a concern over data breaches and privacy including the question, “How is this data going to be used or is it going to be used against the LBGTO community?” PRIDENet is addressing concerns by being very transparent about security with participants.

Health Insight

Sarah Woolsey, MD, FAAFP, Medical Director of Health Insight in Salt Lake City, UT, emphasized the importance of going to the community, and meeting with them where they are and on their timeline. Dr. Woolsey’s research engages very diverse partners from a large number of immigrant communities, including newly arrived refugees. She emphasized the need to be flexible and open-minded, spending time to build relationships and getting to know as well as enjoy the community. She suggested that time spent can serve as a bridge between science and the community. Dr. Woolsey noted that being transparent about funding, budgeting, and results is key to sustaining relationships. As an example, she noted that many immigrants come from communities in which government and others are not transparent and harm communities, and therefore, transparent communication and accountability are critical to relationship-building.



Courtesy of  Health Insight
UTAH

California Center of Excellence for Behavioral Health at UCLA and Healthy African American Families Phase II

Kenneth B. Wells, MD, MPH, Director of the Center for Health Services and Society, Semel Institute for Neuroscience and Health Behavior and Co-Director of the California Center of Excellence for Behavioral Health at UCLA, and Felicia Jones, Program Director for Healthy African American Families Phase II (HAAFII), highlighted a strategy for researchers to use with funders to achieve flexibility. Dr. Wells and Ms. Jones both emphasized the importance of inviting funders and other decision-makers to meetings so they can witness the process of engaging diverse and under-represented partners in research and understand how this is different from traditional studies. They shared this strategy as a way to transparently demonstrate the challenging balance between science and community needs that is inherent in community-partnered participatory research. For example there are often many needs not seen in traditional research approaches that are critical for participatory research—more time, more funds here and there to accommodate and support community participation, and flexibility in the process. Funders need to understand the reasons and observing the process helps build their support.

TOP TIPS

- Encourage others to ask questions whenever something is not clear or when more information is needed.
- Communicate in ways that everyone can understand and make accommodations when necessary.
- Whenever possible, make decisions collaboratively about key project processes.
- When decisions cannot be jointly made, share the reasons why.

Selected Resources

Goodman, L. A., Thomas, K. A., Serrata, J. V., Lippy, C., Nnawulezi, N., Ghanbarpour, S., . . . Bair-Merritt, M. A. (2017). Section three: CBPR values and practices in the domestic violence context. In *Power through partnerships: A CBPR toolkit for domestic violence researchers*. Harrisburg, PA: National Resource Center on Domestic Violence. Retrieved from <https://cbprtoolkit.org>

Program Websites

California Center of Excellence for Behavioral Health at UCLA at <http://hss.semel.ucla.edu/cce/>

COPE (Community Outreach and Patient Empowerment) at <https://www.copeprogram.org/>

HAAFII (Healthy African American Families Phase II) at www.haafii.org

Health Insight (description of its project available on the Patient-Centered Outcomes Research Institute – PCORI) at www.pcori.org/research-results/2016/building-sustainable-pco-and-pcor-community-network-achieve-patient-researcher

PRIDEnet Blog at <https://medium.com/thepridestudy>

Additional Resources

See an **Annotated Bibliography** and an **Annotated List of Resources from the Field** in the Appendices. To view **Spotlight Videos** featuring programs, researchers, and PFC partners, visit the special section of IPFCC's website, [Strengthening Diversity in Research Partnerships](#).

CULTURAL COMPETENCY

Overview

The principle of cultural competency was not outlined as its own distinct principle in the original PCORI principles of engagement. Instead, a commitment to cultural competence was identified as a strategy. Those who informed this guide, made clear the need to elevate cultural competence to its own principle when engaging diverse and under-represented PFC partners in research.

Broadly, culture refers to a pattern of learned beliefs, values, and behaviors that are shared within a group. This pattern, or culture, is not static. Culture cannot be viewed in a vacuum; it can be complex and context is often critical to interacting with and understanding cultural groups. Cultural competence, as such, describes the ability to work effectively with individuals of different cultural backgrounds. It is important to note that cultural competence involves an ongoing process of valuing and respecting others combined with a willingness and openness to change (attitudes and behaviors). It moves beyond a checklist or formula of “do” and “don’t” to development of authentic partnership.

In 1976, Edward T. Hall developed an iceberg analogy or model of culture.¹ Using the image of an iceberg, Hall reasoned that while culture is massive, layered, nuanced and all consuming for each person and community it represents, perhaps only ten percent of that culture, called “surface culture,” is readily visible “above sea level.” The majority of the iceberg, concealed below the water, represents the “deep culture” that includes characteristics such as beliefs, learning styles, assumptions, roles, and patterns of group decision-making.

Hall suggested that the only way to develop an understanding of the deep culture is to take time to get to know people, build relationships, and foster partnerships. This knowledge can then directly guide research—determination of target community/health issues, research questions, study design, analysis, and dissemination activities—with the goal to ultimately facilitate reducing health disparities within a community.

“Taking the time to understand the stories, concepts and values that community leaders and members use to make sense of their relationships and health activities not only provides factors that can be accounted for in intervention and risk models, but more importantly should be used to guide all CBPR activities.”

McMullin, et al., 2010

Strategies & Insights

- **Cultural competency is viewed as more than a checklist and is thoughtfully woven into how all partners approach the project, how they work together, and how research is conducted.**
 - When working with a broad array of diverse PFC partners, cultural competence has a role in every interaction, every communication, and in every stage of the research process. It forms the fabric that binds individuals together.
 - Getting to know, understand, experience, and embrace the culture of all partners on the research team and the target community directly informs the validity of the research. To identify diverse community needs and to develop studies to meet these needs, all partners must spend time coming to know each other, openly communicating, and working effectively together.
 - Acknowledging and addressing historic injustices in research, such as the Tuskegee study and the token role to which diverse partners and communities are often relegated, are critical. While they may have happened many decades ago, such injustices are passed down and carried forward. Therefore, exploring such injustices enables all partners to draw out and examine their own biases and the cultural and historic significance of past research and move forward together as a culturally competent team.
 - By committing to learn about and work toward cultural competency, the principles of honesty, transparency, and trust are also strengthened.
- **Diversity is thought about in expansive terms, drawing from the pulse of the community, not traditional paradigms.**
 - Key informants for this guide implored that diversity be viewed, explored, and discussed in very expansive terms beyond race and ethnicity to reflect a broad view of diversity and culture. In doing so no community is left out and movement can be made in the direction of eliminating all health disparities.
 - The effort has to be made to dive below the ‘surface culture’ and not rely on what one thinks they know about a culture but instead explore the ‘deep culture’ in partnership with a community. Be open to using a broad array of communication and relationship building strategies including listening, hearing, seeing, talking, and thinking.
 - Efforts to explore, experience, understand, as well as enjoy the culture of the people and communities may be time consuming and outside of the traditional research paradigm, but it is crucial to making cultural competence take on a central role.

- **The diversity of the community selected for a study is reflected in the membership of the research team and in the partners involved in all phases of the project.**

- Organizations and research teams should strive to reflect the diversity of the community involved in the project. This was emphasized as a critical component of building trust with diverse partners and essential to advancing research and the translation of research into practice in ways that will address disparities.
- There was a caution expressed by informants to not assume that because a researcher is similar in race, ethnicity, age, gender expression, etc., to a study population that they share the same ‘deep culture’ and therefore can represent a community. Furthermore, subgroups with significant difference can exist within cultures. The perspectives of PFC partners have to be meaningfully included so that ‘deep culture’ can be the guide for research.

“Our partners, the community health representatives were mentoring us, making sure that what we were working on together was meaningful and culturally appropriate.”

Hannah Sehn, Cancer Program Manager
Community Outreach & Patient Empowerment Program (COPE)

Stories from the Field

Northern Arizona University, Center for Health Equity Research

Nicolette Teufel-Shone, PhD, Associate Director of the Center for Health Equity Research, shared a number of culturally sensitive approaches to communication in Native American communities including holding face-to-face meetings, not sending “representatives,” and valuing each voice. Holding in-person meetings, references the Native American tradition of “who is at the table” (meaning being physically present—so that others can see, read, touch, listen) is very important and influences whether Native American partners will speak with researchers, let alone choose to partner with them.

Dr. Emery Eaves, Assistant Professor in Anthropology, echoed the importance of face-to-face contact as she discussed a proposal they are developing related to pain research. In terms of communication methods that promote engagement of Native American communities, Dr. Eaves indicated that she is considering whether or not to include webinars and non-face-to-face methods in the plan.

She shared that much of Native American culture requires and places value on personal contact and ensuring every voice is heard and virtual participation is not seen as helpful. While that may slow the process down, it is important to authentically engage Native American communities in ways that are appropriate to their values and preferences.

Dr. Eaves noted that creating a community-driven agenda for pain research has been challenging for a number of reasons. There is tremendous distrust in Native American communities around research in northern Arizona and there is a lingering distrust between some communities and academic centers, although strong efforts toward community-based research have been improving these relationships. Furthermore, the pain and substance use interventions that exist, are not culturally appropriate or relevant and therefore cause increased feelings of isolation and depression within the community. The intended goal of this project is to create a comparative effectiveness research question based on an intervention that integrates Native American culture and traditions, while also addressing the root causes of pain as well as substance use.

PRIDEnet

One of the cornerstones of PRIDEnet is the emphasis on relationship building through always being welcoming and making sure partners feel they belong. So many in the LGBTQ community have and continue to face rejection and it is a lot to overcome and constantly contend with noted Carolyn Hunt, MPA, Co-Principal Investigator and Community Engagement Director at PRIDEnet. She also shared the value of having organizational leadership who are members of the community. Although it has been challenging, PRIDEnet deliberately works to have a staff directly reflective of the community in terms of gender identity and racial diversity. They also take into consideration diversity in engagement of community partners and in their advisors. They believe that these efforts help to build trust with community and therefore it is worth the time and effort.



PRIDEnet Participant Advisory Committee

UAMS Fay W. Boozman College of Public Health, Department of Health Behavior and Health Education

Keneshia Bryant-Moore, PhD, RN, FNP-BC, Associate Professor at UAMS Fay W. Boozman College of Public Health, shared her experience in a large Delta region mental health research project with the Tri-County Rural Health Network and how that led to her current PCORI-funded work with the FAITH network. The FAITH network is a partnership between faith communities, community-based organizations, and researchers focusing on improving the health of underserved communities in Arkansas. In the previous project they looked to the faith community because of a lack of resources and needed a way to connect the community. In the face of much stigma surrounding mental health diagnoses, many African Americans turn to their pastors. UAMS sought to engage in non-traditional but culturally competent approaches and help move support for mental health treatment to the whole person—mind, body, and soul. Additionally, more colleagues from around the state and the Northwest campus of UAMS have stepped forward to learn from each other and work together on this project. As such, pastors from the Delta are meeting with pastors from the Marshallese community in the northwest region of Arkansas and asking,

“how can we support each other?” Researchers and community partners from UAMS Northwest are adapting strategies so that they align with the Marshallese culture and faith.



Courtesy of UAMS Fay W. Boozman
College of Public Health

TOP TIPS

- Diversity must be thought of in expansive terms.
- Get to know, understand, experience, and embrace the cultures of all partners.
- Acknowledge and address historical injustices in research.

Selected Resources

McElfish, P. A., Long, C. R., Rowland, B., Moore, S., Wilmoth, R., & Ayers, B. (2017). Improving culturally appropriate care using a community-based participatory research approach: Evaluation of a multicomponent cultural competency training program, Arkansas, 2015–2016. *Preventing Chronic Disease*, 14(e62). doi:10.5888/pcd14.170014

McMullin, J., Bone, M., Pang, J. K., Pang, V. K., & McEligot, A. J. (2010). Native Hawaiian voices: Enhancing the role of cultural values in community based participatory research. *Californian Journal of Health Promotion*, 8, 52-62.

Teufel-Shone, N. I., & Williams, S. (2010). Focus groups in small communities. *Preventing Chronic Disease*, 7(3), A67.

Wang-Letzkus, M. F., Washington, G., Calvillo, E. R., & Anderson, N. L. (2012). Using culturally competent community-based participatory research with older diabetic Chinese Americans: lessons learned. *Journal of Transcultural Nursing*, 23(3), 255-61. doi:10.1177/1043659612441021

Program Websites

Center for Health Equity Research at Northern Arizona University at <http://cher.nau.edu/>

PRIDEnet Blog at <https://medium.com/thepridestudy>

UAMS Fay W. Boozman College of Public Health at <https://publichealth.uams.edu/research/current-research-projects/>

Additional Resources

See an **Annotated Bibliography** and an **Annotated List of Resources from the Field** in the Appendices. To view **Spotlight Videos** featuring programs, researchers, and PFC partners, visit the special section of IPFCC's website, [Strengthening Diversity in Research Partnerships](#).

CO-LEARNING

Overview

When originally developed by PCORI, the principle of co-learning included three strategies:

- Researchers help patients to understand the research process
- Team-learning about patient-centeredness and stakeholder engagement
- Incorporation of patient-centeredness and stakeholder engagement into the research process

On their face, the strategies associated with co-learning in this Guide do not appear to be much different. The information and insights we obtained from our literature and resources review and from those whom we interviewed led us to build on these initial strategies and add strategies focused on two critical values—respecting expertise of all and operationalizing co-learning in meaningful ways for all members of the team.

Co-learning, often called bi-directional learning, is increasingly promoted as core to any type of community-engaged research. The intent of this principle is for both PFC partners and researchers to commit to learn from each other. In doing so the expertise of all is recognized, valued, and utilized in order to develop knowledge, skills, and resources that benefit the research. This requires a commitment by all partners to share their perspectives and also to learn from and respect the capabilities of all. Co-learning also relies on consciously designing and embedding opportunities throughout the research process to elicit partners' expertise. The impact of co-learning is both immediate and long-term, ranging from relationship building, knowledge generation, increased engagement, and research questions and methods responsive to a community ultimately leading to findings that can more easily be translated to practice.

There is a genuine desire for researchers and PFC partners to learn from each other, but obstacles often crop up when trying to operationalize co-learning. This may be due to several factors, such as traditional research paradigms, systems that value professional expertise over lived experience, constraints of research timelines and budgets, implicit bias, and mistrust. Co-learning provides opportunities for moving beyond assumptions and accessing deeper understanding of community issues, needs, and priorities.

“The people that we are working with—patients and family caregivers—have extremely valuable and important expertise that academics and medical researchers don’t have. Researchers have their own incredible expertise. Our project brings the shared bodies of expertise together.”

Amanda Young, PhD
Associate Professor
University of Memphis

Strategies & Insights

- **All partners are committed to learning from each other.**
 - When working with diverse partners who have experienced mistreatment and/or are devalued by the health care system, an explicit commitment to learning from each other in all stages of the research process directly supports the principles of trust, honesty, transparency, and the building of partnerships.
 - This particular aspect of co-learning has been described as foundational to cultural competence as it values and formalizes a commitment to learning about and from each person on the research team and from the community; getting to both the surface (norms and elements that can be seen) and deep culture (norms and elements that are not explicit or easily seen).
- **Opportunities exist in all stages of the research process so that all partners are able to continuously learn from each other.**
 - Key informants of this project focused on this strategy as a way to operationalize co-learning, so that learning is ongoing. They shared that planning of such opportunities requires extra time, but that it is the only way to fulfill the commitment to learning and developing sustainable partnerships and ensuring that all research stages are informed by PFC partners.
 - Many shared that the opportunities planned and implemented should be done jointly. In fact, PFC partners should be invited to lead and co-lead the planning and implementation of activities.
- **Efforts are focused on helping PFC partners understand the research process, rather than trying to turn PFC partners into researchers.**
 - Some informants cautioned that development of co-learning efforts could not occur until all partners discussed personal/professional priorities and jointly determined learning goals. While all expressed the need for diverse PFC partners to understand the research process, they stressed that the terms, extent, and purpose of learning must be at the direction of those partners. This changes co-learning from something that is assumed, imposed, and hierarchical to something that empowers, heals, and fosters partnership.
 - PFC partners universally expressed that they only want enough information about the research process to be able to collaborate productively with researchers.

- Several programs offered leadership opportunities to PFC partners that helped prepare them for the research project but more importantly helped them build and strengthen their capabilities. These leadership opportunities benefited the project as well as the individuals. It also benefited communities because often PFC partners become advocates in their communities for participating in research and understanding the significance of research findings.
- Some PFC partners will self-select to build their knowledge and skills to become researchers. Pathways and resources to support their development should be designed and offered.

- **Researchers will learn about patient- and family-centeredness and engagement of PFC partners.**

- This strategy was revised from the original PCORI principles to make this strategy a requirement, rather than a suggestion. Diverse partners and researchers doing CBPR with diverse communities indicated that this learning is at the core of all other principles and one could not realistically happen without the other.
- Many reported that while progress has been made, patient- and family-centeredness and engagement must become non-negotiable aspects of any research aimed at eliminating health disparities for diverse communities. Research that investigates approaches and interventions grounded in patient- and family-centeredness, will lead to a health care system that is truly supportive of a partnership approach to health and health care.



Stories from the Field

Wisconsin Network for Research Support (WINRS), UW-Madison School of Nursing

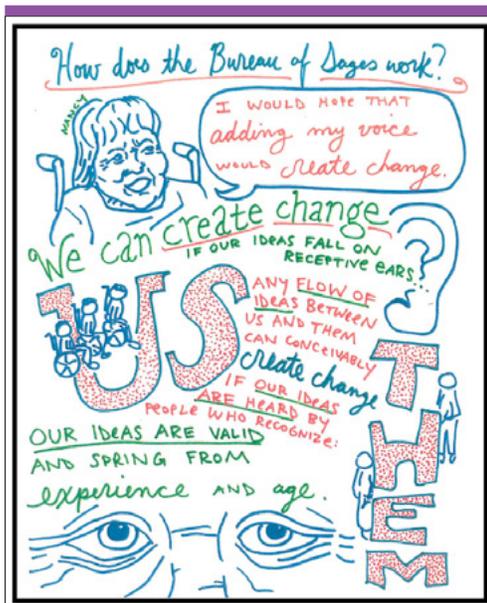
Gay Thomas, MA, Director of Stakeholder Engagement and Betty Kaiser, PhD, Director of Stakeholder Training at WINRS have learned quite a bit in the years they have been engaging individuals from vulnerable and underserved communities in research. They developed an orientation toolkit for patient partners in research which has gone through various iterations. In 2018 WINRS produced the "Patient Advisor Toolkit 1: Orientation for Patient Advisory Committees." Driven by the premise of providing patients with tools, information, and practice that has direct relevance for their role as patient partners, Thomas and Kaiser emphasized the importance of using adult education principles. As such, in orienting patients to engage in research, they advise facilitators to focus on the richness of people's backgrounds and experience, and downplay academic content and didactic presentations. Additionally, they noted the importance of using a script to guide the training, as it is easy to get sidetracked. A script keeps things moving, keeps things fresh, and ensures all objectives are accomplished. A script is especially important for an orientation, as this is the first meeting and sets the tone for researchers and PFC partners working together. If things don't go well in the orientation, the experience is disappointing for all. Furthermore, they noted that orientation is the beginning of a project, but most importantly, it is the beginning of relationship building. Therefore, there must be room for fun, learning about each other, and building a shared sense of community.



Courtesy of WINRS

Leonard Schanfield Research Institute at CJE SeniorLife

The Leonard Schanfield Research Institute at CJE Senior Life in Chicago, IL established the Bureau of Sages, a research advisory board made up of community members from the Lieberman Center for Health and Rehabilitation, elders who participate virtually, clinicians, and researchers. Its purpose is to work together to inform research on aging. She shared that many researchers assume that because someone is in long-term care, they are not cognitively capable of communicating or participating in research. For example, she shared that one geriatrician told her “you can’t partner with people in long-term care because they can’t speak.” Addressing these stereotypes held by researchers and professional providers about the elderly has become essential. Dr. Eisenstein has been surprised by the amount of education and awareness-raising she has had to do on abilities/disabilities knowledge and appropriate accommodations so that the participation of elders is supported.



Drawing by Katharine Houpt, CJE Senior Life

The process to prepare the Sages for research work on the Bureau evolved over time. Although they began with a plan of “how to,” the project team quickly recognized that they needed flexibility and a willingness to change to make things work. Initially the Sages did not understand why researchers would be interested in them and they wondered what they had to contribute to research. The “aha” moment came for many when they realized the value of their lived experience. To reach this “aha” moment and prepare the Sages, the team had to move from a didactic slide presentation educational format to an approach that focused on methods that build on the strengths and preferences of seniors—conversations, storytelling, and relationship building.



Courtesy of CJE SeniorLife

Greenville Health System

At the Greenville Health System (GHS), in South Carolina, Patient Engagement Studios were established to serve as a resource for the GHS Health Sciences Center, serving researchers from four academic partners including Clemson University, Furman University, Greenville Health System, and the University of South Carolina. The purpose of the Studio is “to add patient and community stakeholder perspective to research, include patients as patient ‘scientists,’ and strengthen the quality and relevance of our research.”¹ There is a Main Studio that has been operating for several years. The patient experts in this Studio provide their expertise to many different projects and these are typically short-term collaborations with researchers. Additional condition-specific Studios have been created in order to allow work to extend over the course of several months and these have focused on rheumatoid arthritis, breast cancer, and diabetes. These studios engage diverse patients and family caregivers, including those from different cultures, communities (e.g., rural), and with differing types and severity of conditions.



Greenville Patient Engagement Studio

The two researchers who lead and facilitate the Studios, Peggy Wagner, PhD, and Ann Blair Kennedy, DrPH, provide orientation for the patient experts. They spoke about the importance of orienting and preparing individuals for their roles as patient experts but not in a didactic manner. This onboarding is carefully and thoughtfully conducted and activities are selected to assist the patient experts to not only learn about their own condition but to also develop skills to share their perspectives about what matters most to them. Some of the patient experts who were engaged in the diabetes studio talked about how they didn’t initially understand how the activities were connected to actual research. Once they began to present their ideas for research questions to researchers, they quickly recognized how all of the activities they participated in led up to that point. For example, in one activity they took photos of four items that were important to them in managing their condition.

“This has increased my passion for learning more about this disease and sharing with those around me in my community, my church, and wherever I can help. I like the idea of what I’m doing here. I can pass it on.”

Phoebe Roberts, Patient Expert, Greenville Health System

¹ Greenville Health System – Health Sciences Center (n.d.). What does partnering with the Studio look like? Retrieved from <https://hsc.ghs.org/research/pes/study-look-like/>



Laurens Patient Engagement Studio

In a subsequent Studio meeting they shared the photos and their thoughts about the significance of the items with the group. These photos later provided compelling images and messages to illustrate the overarching themes of the research questions they had developed over several months. As Nikki Ward, a patient expert in the Laurens Patient Engagement Studio shared, “in the last few sessions when we worked with a researcher who helped us develop the questions, I can see where we pulled all of what we’ve done in previous sessions together.” Dr. Wagner also shared that the patient experts had helped her learn, “I don’t even have diabetes and this group has changed me.”

University of Arkansas for Medical Sciences, Fay W. Boozman College of Public Health

Kate Stewart, MD, MPH, professor in the Department of Health Policy and Management at UAMS Fay W. Boozman College of Public Health in Little Rock, shared that the community partners provide education to researchers to help build their skills to partner with diverse communities. She outlined one workshop that their Prevention Research Center’s Community Advisory Board developed and offer several times a year to researchers, “Do’s and Don’ts of Community Engagement.” The workshop is broken into three important parts—entering the community, the realities of being a community-based organization, and dissemination of research. It incorporates methods such as real life scenarios and reverse role-playing. She shared that this workshop has helped shift the paradigm in part because the role-playing is fun and lightens the mood, helping people be more open to change.

TOP TIPS

- Use adult learning methods and limit didactic methods for co-learning.
- Support PFC Partners and researchers to build an understanding of the expertise of all partners.
- Continuously conduct co-learning activities based on the priorities and goals of all partners.

Selected Resources

CERTAIN Patient Advisory Network's INSPIRE Research Portal at <http://inspireresearch.org/>

CJE SeniorLife, Leonard Schanfield Research Institute. (2017, October). *How to talk about research: A training toolkit for nursing home residents and stay-at-home elders*. Retrieved from <https://www.pcori.org/sites/default/files/Bureau-of-Sages-Training-Toolkit.pdf>

Joosten, Y. A., Israel, T. L., Williams, N. A., Boone, L. R., Schlundt, D. G., Mouton, C. P., . . . Wilkins, C. H. (2015). Community engagement studios: A structured approach to obtaining meaningful input from stakeholders to inform research. *Academic Medicine, 90*(12), 1646–1650. doi:10.1097/ACM.0000000000000794

Kaiser, B., & Thomas, G. (2018). *Patient advisor toolkit 1: Orientation for patient advisory committees (PAT-1)*. Madison, WI: Wisconsin Network for Research Support, University of Wisconsin – School of Nursing, and Health Innovation Program. Available at <https://www.hipxchange.org/PAT-1>

Program Websites

Bureau of Sages at Leonard Schanfield Research Institute at CJE Senior Life at www.cje.net/research-education/bureau-sages

Patient Engagement Studio at Greenville Health System at <https://hsc.ghs.org/research/pes/>

UAMS Fay W. Boozman College of Public Health at <https://publichealth.uams.edu/research/current-research-projects/>

Wisconsin Network for Research Support at <https://winrs.nursing.wisc.edu/>

Additional Resources

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PARTNERSHIPS

Overview

The principle of partnerships is at the very heart of all forms of community-based and patient/family-engaged participatory research. To authentically practice this approach, all partners recognize that each has expertise to contribute, value shared decision-making, and strive to achieve collaborative ownership of the project. Through the information gathered for this guide from all researchers and PFC partners, three critical values of partnership in research emerged: fairness of time request and compensation lead to equality; accessibility and inclusion necessitate accommodation; and commitment and support of leadership promotes and sustains partnerships.

Partnerships in research that engage diverse PFC partners are based on equality and shared responsibility. Getting to those foundations requires time, resources, flexibility, and openness. It requires leadership that is committed and supportive. Many key informants and articles reviewed for this Guide underscored that equal contribution is the key to not only partnership in research, but also to eliminating health disparities and achieving health equity. This equal contribution does not equate to resources but instead refers to recognition of expertise and leadership. Many shared that all partners benefit from respecting each others' knowledge, embracing shared development of mechanisms to translate knowledge into action within communities, and building a relationship in which knowledge is freely exchanged and positive change occurs.

Researchers and PFC partners alike indicated that true partnership cannot be achieved through traditional research paradigms in which there is a hierarchy of power. There is a need to create a level playing field in which PFC partners are supported to participate to the level they choose. This can happen through ensuring that the contributions of all partners are acknowledged, requests for time and effort are reasonable, fair compensation is provided, and accommodations are made to facilitate participation.

"We were told about this idea of equalizing roles and breaking down the hierarchies because then you can truly understand each other... and build community and trust. Once you've got that there's a real foundation to move your engagement and research efforts forward."

James Harrison, PhD
Assistant Professor
UCSF Division of
Hospital Medicine

Strategies & Insights

- **Requests for time commitment of PFC partners are reasonable, respectful, and flexible.**
 - Many indicated that a valuable lesson learned about time is that it can be very influenced by culture. Therefore the concept of time should be explored and openly discussed with PFC partners so that expectations are reasonable. If meeting or project activity schedules are created based on assumptions and not explicit information, efforts can be derailed.
 - Many shared that to properly and authentically partner in research, it is necessary to remain flexible with timelines. It is helpful to plan timelines jointly with diverse partners and include some space in the timeline at critical milestones and to account for changes and revisions that may be needed. In traditional research, flexibility is often not valued. Openly discuss with funders the reasons that adjustments may need to be made throughout a study (and even invite them to observe meetings or other project activities).
- **PFC partners receive fair financial compensation for their participation.**
 - Although this has always been a strategy of partnership for engaging PFC partners in research, those collaborating with diverse partners indicate that this strategy is of particular importance when working with underserved and vulnerable communities. Many informants indicated that lack of fair compensation for time and efforts of diverse partners created hierarchy (or a power dynamic) and devaluation of PFC partners that could in fact erode or prevent formation of trust and partnership. Of note, this was documented not only by researchers who “learned the hard way” but also by PFC partners. When PFC partners addressed this issue they came from two different perspectives, “why do they get paid and we get nothing for giving of our time, knowledge, experience, and community” and genuine surprise when researchers did fairly compensate (based on their experience with being asked over and over to “volunteer” their time).
 - For many PFC partners compensation is necessary. Without this, they may not be able to afford to participate—factors such as the time they can’t be working, child or respite care for a family member, and transportation are costs that they can’t afford and shouldn’t be their responsibility.

- **Researchers meet diverse PFC partners “where they are” and honor their preferences for level and types of engagement.**

- “Where they are” speaks to the need to get to know diverse PFC partners to make sure that engagement efforts and inclusion in research recognizes and meets needs, abilities, and interests of diverse PFC partners, rather than trying to use a “one size fits all” approach. This is of particular importance in many communities that have a history of mistreatment and distrust of research. Failure to listen to, get to know, and include in meaningful ways that align with the preferences and priorities of PFC partners can create a sense of tokenism.
- “Where they are” also speaks to the need to meet with diverse partners in the geographic location of their community whenever possible. This aspect of “where they are” was identified as important to PFC partners for several reasons including they are more likely to engage in their own community in familiar, trusted settings; transportation issues are more easily managed, and it levels the power dynamic that can be present when entering an academic or institutional setting. Many informants shared that going to “where they are” may not be as critical if the partnership extends over a long period of time and a solid relationship has been built.

- **Accessibility and inclusiveness are viewed broadly and accommodations are planned and implemented to support engagement.**

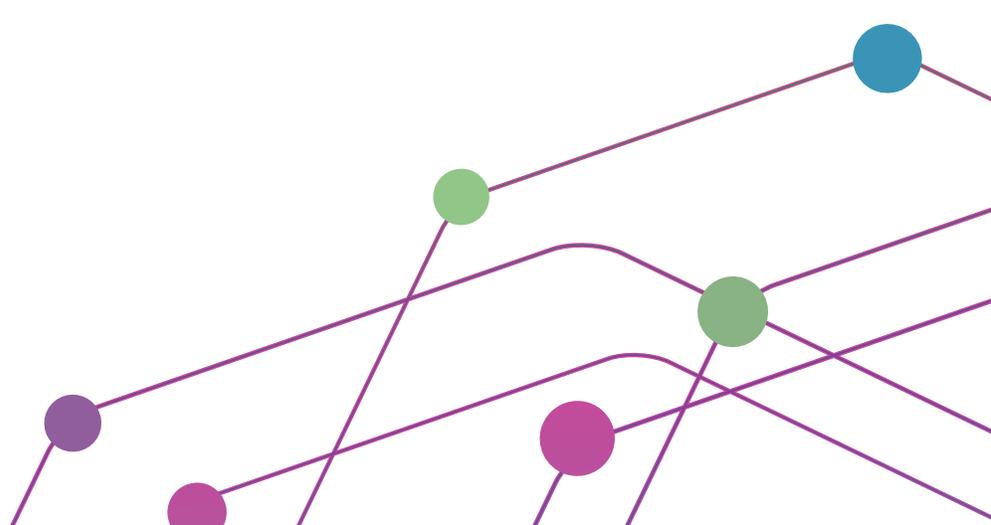
- Key informants stressed the need for accessibility and inclusiveness in not only traditional terms, such as physical access to a location for a person using a wheelchair or interpreters, but also in broad terms that include being responsive to factors such as culture or health status.
- The need for accommodation should be discussed between researchers and PFC partners so that needs are clearly known and creative shared solutions can be identified, planned for ahead of time, and implemented. Such discussions assist all to both plan and be flexible because many accommodation needs are ongoing and ever changing (e.g., dependent on health status).
- Additionally, partners emphasized that a big part of accessibility and inclusion involves seeing worth, value, and ability in each and every person regardless of education, socio-economic status, health/disability, or other characteristics. Some researchers noted that a great deal of effort raising awareness within their peer group, as well as with funders, is needed.

- **The commitment and support of leadership in research and stakeholder organizations are viewed as essential to build and sustain engagement of PFC partners.**

- Although funding was often identified as critical to sustaining projects and partnerships, key informants delved into this a bit more to highlight that leadership commitment and support is in fact the most powerful tool. Many noted that this also takes time and a lot of co-learning and education, but that once leadership support and commitment align with the needs and priorities of diverse communities, then anything is possible.
- A common concern that PFC partners expressed was that their participation typically ends when a research study is completed. Because of their investment of time and effort and the development of a trusting relationship over the course of a project, it was difficult for them to not be able to continue the partnership. Several researchers recognized this and are trying to come up with creative strategies to resolve this issue (e.g., providing funds directly to community agencies to build sustainable infrastructure that will support ongoing involvement of PFC partners after a project ends but when continued dissemination of findings to the community is beneficial).

“This is the way research is going to be approached, with patients involved. Patients need to embrace this and take part whenever they have an opportunity. This will be the research of the future.”

Johnny Payne, Patient Expert, Greenville Health System



Stories from the Field

Healthy African American Families Phase II

Felicia Jones, Program Director, Healthy African American Families Phase II (HAAFII) spoke about HAAF's founder, Loretta Jones, and her belief that all the right people—those who can make change happen—need to be at the table.



Courtesy of HAAFII

Everybody needs to have a voice and have equal partnership. At HAAFII they strive for a ratio of two community partners to every one academic representative in projects so as to equalize the power dynamic. In addition, they believe it is important to broadly determine who has to be there. Funders and policy makers won't understand on paper how the work gets done so they are invited to meetings in order to see the process. They have changed minds with this approach.

Ms. Jones indicated that stipends are required for community partners because it demonstrates that their intellectual property is valued. Everyone else is being paid to be at the meeting and this is not just an altruistic pursuit for community partners. As part of valuing each person, Ms. Jones noted that sometimes the community members cannot maintain consistent engagement because of their personal and professional commitments. They try to balance the in-person meetings with phone calls. Ms. Jones views a project as a bus always in motion. People get on and off the bus, but the bus keeps moving. For a variety of reasons, community partners hop on and off as needed, but HAAFII is committed to keeping everyone informed. Meeting minutes and other information are sent out so people can stay updated. As Ms. Jones reported, these efforts to keep everyone engaged "takes energy—we have working group meetings and conference calls and we have team building activities such as retreats with fun activities. We want to bring the light back to everybody." It's important



Courtesy of HAAFII

to encourage bi-directional learning so that everyone feels comfortable and recognized. As she stated, "I have value, you have value, and no one is more important...we are looking for where the win-win is for this community and everyone in this partnership. What is your win personally, professionally, for the project?" HAAFII uses a number of interactive strategies including icebreaker activities to prompt discussion.

Wisconsin Network for Research Support (WINRS), UW-Madison School of Nursing

With regard to biggest challenges they have faced at WINRS, Gay Thomas, Director of Stakeholder Engagement and Betty Kaiser, PhD, Director of Stakeholder Training at WINRS reflected inwards, “us.” They noted that while they had previously used the label, “hard to reach communities,” they now have an aversion to the label because in fact, “they aren’t hard to reach as they are right before us in their communities.” The issue is more about putting yourself out there to connect with diverse partners who are known and trusted in the community. To support these outreach efforts, they noted the importance of carefully selecting the meeting venue, using plain language, communicating clearly and respectfully, paying people for their time, building strong relationships with community organizations, and ensuring that the researchers have the right skills to engage, co-learn, and support.

They also shared that consistency can be a challenge. In running their CARDS® (Community Advisors on Research Design and Strategies), they rely on liaisons within community centers to provide continuity and provide a facility fee to each center to cover the cost of the liaison and the meeting space rental. The liaisons handle meeting attendance, participate in meetings, and arrange necessary childcare and transportation. They shared that one of the liaisons left her position and caused a disruption in the process. Consistency is important for maintaining trust and comfort, as familiarity ensures people can/will speak up and speak freely. This consistency is important to CARDS members in other ways including their preference to have the same facilitator(s) lead meetings as this allows trust and relationships necessary to the research partnership to build.



Courtesy of WINRS

Northern Arizona University, Center for Health Equity

Emery Eaves, PhD, from the Center for Health Equity Research discussed a few issues that she believes support engagement. She emphasized the importance of compensating PFC partners for their time and efforts. She indicated that not only is it a fair and equitable practice, but it also makes clear that there is equal footing between professional and community partners. She emphasized that compensating for time and reimbursing for expenses demonstrates to community partners that they too are valued, respected, and considered experts crucial to a project. She indicated that building compensation into a project budget is key. Additionally, she suggested looking at how researcher time is valued and compensated; making sure that the compensation of partners is directly parallel.

UAMS Fay W. Boozman College of Public Health, Department of Health Policy and Management

Kate Stewart, MD, MPH, Professor in Department of Health Policy and Management reflected back on more than 20 years of experience in community-based participatory research (CBPR) and engaging with diverse and under-represented partners in research. She commented on how so much has changed, and yet how certain values or principles of engagement have not changed. For example, Dr. Stewart emphasized the importance of leadership. Leadership must be supportive and “buy in” to community engagement for the engagement to be successful, to continue to move forward, and build lasting infrastructure. Leadership must assist in pursuing funding for sustainability. Furthermore, Dr. Stewart reflected on the changing landscape of funding support for CBPR and comparative effectiveness research, and remarked that funders like PCORI have dramatically helped shift the tides to community engagement by attaching funding to the requirement for engagement.

Dr. Stewart also shared that building authentic relationships with community members and agencies over time is critical. As part of this, when working with community partners with a history of discrimination or experiences of stigma and exclusion, for example rural African-Americans or transgender communities, she emphasized the need for honesty, transparency, and trust building. She noted that helping communities obtain financial resources to address issues that matter most to them can be a successful approach to trust building and that listening to what their priorities are is critical in this regard.

“By implementing intentional structural supports (i.e., community-academic partnerships, community advisory board, community health worker model, health registry, resource directory, research collaborative), we were able to engage the broader community in research and successfully reach populations with disproportionate health burdens.”

Stewart et al., 2015, Preventing Chronic Disease

TOP TIPS

- Flexibility, although challenging in research, is invaluable to partnership.
- Fair financial compensation is key to equality of all partners.
- Viewing accessibility and inclusion broadly ensures everyone is included.

Selected Resources

Durham Community Research Team, Centre for Social Justice and Community Action, Durham University. (2011). *Community-based participatory research: Ethical challenges*. Durham, UK: Author. Retrieved from <https://ahrc.ukri.org/documents/project-reports-and-reviews/connected-communities/community-based-participatory-research-ethical-challenges/>

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Stewart, M. K., Felix, H. C., Olson, M., Cottoms, N., Bachelder, A., Smith, J., . . . Greene, P. G. (2015). Community engagement in health-related research: A case study of a community-linked infrastructure, Jefferson County, Arkansas, 2011-2013. *Preventing Chronic Disease*, 12, e15. doi:10.5888/pcd12.140564

Program Websites

CHER (Center for Health Equity Research) at Northern Arizona University at <http://cher.nau.edu/>

HAAFII (Healthy African American Families Phase II) at www.haafii.org

UAMS Fay W. Boozman College of Public Health at <https://publichealth.uams.edu/research/current-research-projects/>

WINRS (Wisconsin Network for Research Support) at <https://winrs.nursing.wisc.edu/>

Additional Resources

See an **Annotated Bibliography** and an **Annotated List of Resources from the Field** in the Appendices. To view **Spotlight Videos** featuring programs, researchers, and PFC partners, visit the special section of IPFCC's website, [Strengthening Diversity in Research Partnerships](#).

CONCLUSION

This two-year project funded by a Eugene Washington PCORI Engagement Award from the Patient-Centered Outcomes Research Institute® (PCORI®) was an incredibly rich and rewarding learning process for the project team.

Planning, conducting, and disseminating research in true partnership with communities that historically have been under-represented in research requires a fundamental shift in the culture, beliefs, and practices of traditional research. The original Principles of Engagement created by PCORI provided a helpful lens with which to begin to explore best practices within exemplary organizations. Due to the unique circumstances of diverse individuals and communities who have been under-represented, marginalized, or even harmed by research, the project team endeavored to expand and enhance the Principles of Engagement and develop key strategies based upon the insights and lessons learned from those who are engaged in authentic and productive partnerships.

It was clear from all of the experts—patient, family, and community partners and researchers—who shared their wisdom that developing meaningful and authentic partnerships takes leadership, time, resources, flexibility, and most importantly, a firm commitment to be open to learning from each other. As Scott Noble, a person with lived experience who is a research leader and member of the Leadership Advisory Board at Chicago Health Disparities Center at the Illinois Institute of Technology stated, “the community knows what the community needs better than it being forced upon them.” By engaging in true partnerships we will be better equipped to design and conduct research that ultimately leads to knowledge benefiting all and fostering the elimination of disparities existing in health and health care.

“As academic health centers seek to expand their goals to embrace a model that promotes health as well as health care, it is imperative to integrate community-engaged research.”

McElfish et al., 2015

“One of the biggest transitions is that research begins to go from the head to the heart. That’s the research that matters... what you’re connected to on a deeper level.”

Sonya Ballentine, Lived Experience Research Leader
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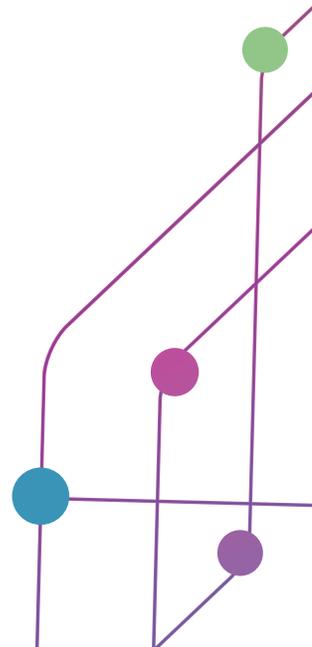
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ANNOTATED BIBLIOGRAPHY

Overviews and Conceptual Frameworks for Partnerships with Under-Represented Communities

The articles in this section provide a valuable and broad view of models for engaging typically under-represented patient, family, and community partners in planning and conducting research.

Belone, L., Lucero, J. E., Duran, B., Tafoya, G., Baker, E. A., Chan, D., . . . Wallerstein, N. (2016). Community-based participatory research conceptual model: Community partner consultation and face validity. *Qualitative Health Research, 26*(1), 117-135. doi:10.1177/1049732314557084

This article provides results of community input to assess the face validity and acceptability of a conceptual model of community-based participatory research designed to understand the contribution of partnership processes to improved community capacity and health outcomes. Results include a revised model, validated and expanded, with four additional “real-world” constructs added: trust development, capacity, mutual learning and power dynamics. Of note is the capacity to adapt the model to diverse contexts.

Boyer, A. P., Fair, A. M., Joosten, Y. A., Dolor, R. J., Williams, N. A., Sherden, L., . . . Wilkins, C. H. (2018). A multilevel approach to stakeholder engagement in the formulation of a clinical data research network. *Medical Care, 56*(10 Suppl 1), s22-s26. doi:10.1097/MLR.0000000000000778

This article discusses the multilevel framework for engaging stakeholders used in Phase I of the development of the Mid-South Clinical Data Research Network. Stakeholders serve in roles as varied as integral research team members, advisory committee members, consultants, and respondents to surveys/interviews. As a result, a number of lessons were learned and effective approaches developed including the following: involve stakeholders early in the planning process, provide bi-directional preparation, and make use of effective communication methods.

Corbie-Smith, G., Wynn, M., Richmond, A., Rennie, S., Green, M., Hoover, S. M., . . . Nisbeth, K. S. (2018). Stakeholder-driven, consensus development methods to design an ethical framework and guidelines for engaged research. *PLoS One, 13*(6), e0199451. doi:10.1371/journal.pone.0199451

This study used a multi-stage process to develop a much needed framework and recommendations for the ethical review and conduct of research that engages stakeholders in the research process. Their approach included a literature review, case studies; a consensus development workshop with participants representing IRB, academic institutions, and community organizations; interviews; and an online survey. Four domains form the anchors of the framework—vision of equitable and just research, relationship dynamics, community-informed risks/benefits assessment, and accountability.

Decter, M., & Brown, A. (Eds.). (2018). Engaging patients in health research: The Ontario experience [Special issue]. *CMAJ, 190*(Suppl. 1), S1-S56. Retrieved from <http://www.cmaj.ca/content/suppl/2018/11/02/190.Suppl.DC2>

This special issue features 19 articles describing 17 diverse research projects in which researchers are partnering with patients, families, and communities in Ontario. The projects were funded by the Canadian Institutes of Health Research through the Strategy for Patient-Oriented Research. Topics covered include mental health, Indigenous health, pediatrics, geriatrics, and complex chronic conditions. While partnerships are a newer process for many of the teams, the articles describe the successes, challenges, and future steps.

Durham Community Research Team, Centre for Social Justice and Community Action, Durham University. (2011). *Community-based participatory research: Ethical challenges*. Durham, UK: Author. Retrieved from <https://ahrc.ukri.org/documents/project-reports-and-reviews/connected-communities/community-based-participatory-research-ethical-challenges/>

The Durham Community Research Team used a scoping study to examine ethical issues in CBPR. The study showed significant range of approaches claiming to be participatory and community-based, and therefore, similarly demonstrated variation in degrees of participation and community control. Some of the ethical challenges identified included partnership, collaboration, power, and ownership and dissemination of data. The article closes by setting forth recommendations such as: adoption of ethical guidelines for CBPR for researchers, funders, and sponsors and further research on CBPR outcomes.

Kauffman, K. S., dosReis, S., Ross, M., Onukwugha, E., & Mullins, C. D. (2013). Engaging hard-to-reach patients in patient-centered outcomes research. *Journal of Comparative Effectiveness Research, 2*(3), 313-324. doi:10.2217/cer.13.11

Authors discuss key findings from a PCORI study to identify methods for including hard-to-reach populations in research design, implementation, and dissemination. Key recommendations for meaningfully engaging patients in patient-centered outcomes research include, but are not limited to: bring research to communities where people live; use a period of 'pre-engagement' when recruiting research participants and partners; involve full spectrum of people that will be affected by the research, including hard-to-reach patients; build and maintain trust for active patient engagement; provide education on what is meant by the term research; keep people up-to-date on research progress; and make a sincere effort to 'give back' to the community.

McElfish, P. A., Kohler, P., Smith, C., Warmack, S., Buron, B., Hudson, J., . . . Rubon-Chutaro, J. (2015). Community-driven research agenda to reduce health disparities. *Clinical and Translational Science, 8*(6), 690–695. doi:10.1111/cts.12350

This paper describes how the University of Arkansas for Medical Sciences set a community-driven research agenda for the entire Northwest Campus using a CBPR process to address the significant health disparities faced by the growing Marshallese and Hispanic populations. Within 18 months of this unique process and agenda formulation, the results were dramatic including initiation of nine research projects and health programs.

Wallerstein, N., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*(3), 312-323.

The authors dive deep into the tension and challenges that arise surrounding the mutuality of the research relationship as CBPR matures in its implementation. They explore the dynamics of power, privilege, participation, community consent, and racial and/or ethnic discrimination in the researcher-community relationship and discuss evidence that CBPR reduces disparities. The authors also recommend ways to transform the culture of academia to strengthen collaborative research relationships.

Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health, 100*, S40-46. doi:10.2105/AJPH.2009.184036

This article directly lays out how CBPR can respond to at least six core challenges of translational research. These include partnering with community members to best contextualize an intervention for specific settings, integrating cultural values and practices to enhance sustainability when grant funding ends, and ultimately, democratizing science by valuing communities as equal contributors to the knowledge production process. In so doing, CBPR can play an important role in expanding the reach of translational intervention and implementation sciences to influence practices and policies for eliminating disparities.

Specific Strategies for Engagement of Under-Represented Patient, Family, and Community Partners in Research

This section includes articles that relate to the seven engagement principles used to frame the Strengthening Diversity in Research Partnerships: Knowledge to Action Guide—trust, reciprocal relationships, honesty, transparency, cultural competency, co-learning, and partnerships. At the end of each summary, we have included the engagement principle to which the article is most relevant.

Chatwood, S., Paulette, F., Baker, R., Eriksen, A., Hansen, K. H., Eriksen, H., . . . Brown, A. (2015). Approaching *Etuaptmumk* — Introducing a consensus-based mixed method for health services research. *International Journal of Circumpolar Health*, 74, 27438. doi:10.3402/ijch.v74.27438

In response to lack of documentation of research methods and theories based on Indigenous knowledge in academic texts and peer-reviewed literature, this article articulates the use of a consensus-based, mixed-method with indigenous knowledge built on the principles of *Etuaptmumk* or two-eyed seeing. The authors illustrate how mixed methods' frameworks allow for developing research questions appropriate to obtain data from both Indigenous and western knowledge sources. [Trust]

Cheney, A., Haynes, T., Olson, M., Cottoms, N., Bryant, K., Reaves, C., . . . Sullivan, G. (2018). Using deliberative and qualitative methods to mobilize community around the mental health needs of rural African Americans. *Health Systems and Reform*, 4(1), 8-18. doi:10.1080/23288604.2017.1404180

By combining the deliberative process of Democracy Forums with rigorous qualitative methods, this project demonstrates how this unique combination has the power to unite diverse community members around a shared sense of purpose and move them to action. The authors pay particular attention to detailing how the combined process empowers diverse communities to identify solutions and produce evidence grounded in both individual and collective experience. [Reciprocal relationships]

Christopher, S., Watts, V., McCormick, A. K., & Young, S. (2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health*, 98(8), 1398-1406. doi:10.2105/AJPH.2007.125757

Co-authored by community and academic partners, this article focuses on tangible ways trust was built and maintained through CBPR processes between the Crow Indian Nation and Montana State University. Choosing to acknowledge past experiences and history, the research partners focused on two levels of trust—between the university and community partners and between the initial project team and the larger community. Many powerful strategies to build and maintain trust were identified including being present in the community and listening, being upfront about expectations and intentions, and matching words with actions. [Trust]

Corrigan, P., Pickett, S., Kraus, D., Burks, R., & Schmidt, A. (2015). Community-based participatory research examining the health care needs of African Americans who are homeless with mental illness. *Journal of Health Care for the Poor and Underserved*, 26(1), 119-133. doi:10.1353/hpu.2015.0018

This article describes the findings of the CBPR team that conducted focus groups to elicit the needs and problems of African Americans with mental illness who are homeless and experience significantly higher morbidity and mortality rates. Resulting themes were divided into needs and solutions, which in turn were used to develop more CBPR and interventions. [Trust]

Davis, J. L., McGinnis, K. E., Walsh, M. L., Williams, C., Sneed, K. B., Baldwin, J. A., & Green, B. L. (2012). An innovative approach for community engagement: Using an Audience Response System. *Journal of Health Disparities Research and Practice*, 5(2), pii 1.

The authors present the potential benefits of a tool such as Audience Response Systems (ARS) as an innovative way to engage the community and obtain data. The article outlines the results when ARS was implemented at a community town hall event sponsored by a National Institute on Minority Health and Health Disparities Exploratory Center of Excellence, the Center for Equal Health. Overall participants appreciated being able to see how everyone else answered and felt included in the research process. ARS enabled the community to answer truthfully and provided instant research results. [Partnerships]

Ferre, C. D., Jones, L., Norris, K. C., & Rowley, D. L. (2010). The Healthy African American Families (HAAF) Project: From community-based participatory research to community-partnered participatory research. *Ethnicity & Disease, 20*(1 Suppl 2), S2-1-8.

This article details the long history and lessons learned from a community-partnered participatory research project, HAAF, that began as a partnership between a local community advisory board, university, and federal agency and grew into an independent, incorporated community organization that brokers research and health promotion within its community. Building upon already-existing community resiliency and resources, centuries of self-help, problem-solving, and cooperative action, HAAF created a model with partnering, mutual ownership, responsibility, liability, and benefit at the core. It is into this framework that HAAF has integrated mutual support, research, and interventions. [Reciprocal relationships]

Hicks, S., Duran, B., Wallerstein, N., Avila, M., Belone, L., Lucero, J., . . . White Hat, E. (2012). Evaluating community-based participatory research to improve community-partnered science and community health. *Progress in Community Health Partnerships: Research, Education, and Action, 6*(3), 289–299. doi:10.1353/cpr.2012.0049

This research team presents a paper based on a multi-year study conducted by the National Congress of American Indians Policy Research Center, the University of New Mexico, and the University of Washington focused on the science of community-based participatory research and facilitators and barriers to community-academic partnerships particularly for communities facing health disparities. Lessons learned include topics such as effective use of advisory committees, honoring each other, capacity development, advocacy, trust, and the importance of clear communication to the community about the benefits. [Partnerships]

Huang, J., Lipman, P. D., & Mullins, C. D. (2017). Bridging the divide: Building infrastructure to support community-academic partnerships and improve capacity to conduct patient-centered outcomes research. *Translational Behavioral Medicine, 7*(4), 773-782. doi:10.1007/s13142-017-0487-z

This article details the PATIENTS program established at the University of Maryland, Baltimore, as a model for research that is participatory, rather than just “community placed.” They describe an infrastructure that has proved successful in efforts to build a skilled PCOR community and fostering sustainable partnerships between diverse communities and health care systems. The article also shares nine lessons learned, such as mentorship for capacity building and how it is never too early to think about sustainability. [Partnerships]

Huff-Davis, A., Cornell, C. E., McElfish, P., & Yearly, K. H. (2018). Strategies to facilitate equitable resource sharing in community-engaged research. *Progress in Community Health Partnerships, 12*(2), 173-177. doi:10.1353/cpr.2018.0037

Using the implementation of one Federal grant as a backdrop, this case study describes the barriers and strategies to implementing community sub-contracts. Authors share lessons learned at the community-based organization, budget creation, and university levels. Critical to community-engaged research, this article calls for institutional changes to facilitate equitable resource sharing. [Partnerships]

Joosten, Y. A., Israel, T. L., Williams, N. A., Boone, L. R., Schlundt, D. G., Mouton, C. P., . . . Wilkins, C. H. (2015). Community engagement studios: A structured approach to obtaining meaningful input from stakeholders to inform research. *Academic Medicine, 90*(12), 1646–1650. doi:10.1097/ACM.0000000000000794

Recognizing that researchers are often not sufficiently trained in how to identify, recruit, convene, and prepare community partners for collaborative research, Vanderbilt University developed the “Community Engagement Studio” approach. Detailed in this article, along with a summary of outcomes, the authors discuss the background, process, and flow of engaging the community through this approach. [Co-learning]

Kelley, M. L., Prince, H., Nadin, S., Brazil, K., Crow, M., Hanson, G., . . . Smith, J. (2018). Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care. *Annals of Palliative Medicine*, 7(Suppl 2), S52-S72. doi:10.21037/apm.2018.03.06

Using a Participatory Action Research Integrative Framework for Conducting Research with First Nations, this study created culturally appropriate, community-based palliative care programs in four communities. Findings included new results about the importance of place (e.g., caregiving networks), leadership, education and sense of community as keys to success. Furthermore, the authors noted that through the use of PAR, they found evidence of the critical role of culture in capacity development. [Cultural competency]

Khodyakov, D., Mikesell, L., & Bromley, E. (2017). Trust and the ethical conduct of community-engaged research. *European Journal for Person-Centered Healthcare*, 5(4), 522–526. doi:10.5750/ejpc.v5i4.1263

Using multiple methods, the authors describe trust as a core concept of the ethical conduct of community engaged research, highlight its benefits, explore risks associated with reliance on trust in the research process and offer the ways in which community engaged research can increase public trust in science and research, including those minority populations victimized by past ethical misconduct in research. [Trust]

Maar, M., Boesch, L., & Tobe, S. (2018). Enhancing Indigenous health research capacity in northern Ontario through distributed community engaged medical education at NOSM: A qualitative evaluation of the Community Engagement Through Research pilot program. *Canadian Medical Educational Journal*, 9(1), e21-e32

The Community Engagement Through Research (CETR) program uniquely matches medical students and members of Indigenous communities to explore their own research questions. This article outlines the program, discusses lessons learned and barriers, such as time and resource constraints, while also noting that all participants felt inspired and found meaning. [Reciprocal relationships]

McElfish, P. A., Long, C. R., Rowland, B., Moore, S., Wilmoth, R., & Ayers, B. (2017). Improving culturally appropriate care using a community-based participatory research approach: Evaluation of a multicomponent cultural competency training program, Arkansas, 2015–2016. *Preventing Chronic Disease*, 14(e62). doi:10.5888/pcd14.170014

This article shares the results of an evaluation of a Marshallese and Hispanic cultural competency training delivered to 25 organizations in a region that have high numbers of both of these groups. Mixed method evaluation revealed both positive changes in knowledge and behavioral changes. Training modules were developed and conducted by multiple partners including Hispanic, Marshallese, and health care and academic professionals allowing for the most important concerns, needs, and priorities of each group to be incorporated into the training. [Cultural competency]

McElfish, P. A., Moore, R., Laelan, M., & Ayers, B. L. (2018). Using CBPR to address health disparities with the Marshallese community in Arkansas. *Annals of Human Biology*, 45(3), 264-271. doi:10.1080/03014460.2018.1461927

This article describes the formation of a CBPR partnership with the Marshallese community in Arkansas and outlines the key lessons learned over the five-year partnership. Lessons learned are grouped into seven key areas and explored: intensive involvement of Marshallese in a variety of sectors and roles of research, interprofessional teams, churches, consideration of sex, family and definition of family, qualitative methods that respect cultural traditions, and cultural humility. [Reciprocal relationships and Cultural competency]

McMullin, J., Bone, M., Pang, J. K., Pang, V. K., & McEligot, A. J. (2010). Native Hawaiian voices: Enhancing the role of cultural values in community based participatory research. *Californian Journal of Health Promotion, 8*, 52-62.

Community voices guided this paper that argues Native Hawaiian values intersect with and promote goals of CBPR, such as equality, respecting strengths, and eliminating health disparities. This study placed Native Hawaiian values associated with concepts such as “aloha” and “ano ano hua” equitably side by side with scientific values and in turn demonstrated that community concepts are more than variables to be added to analysis. Rather, community concepts can both be parallel to and extend the inherent goals of CBPR. [Cultural competency]

Norman, N., Bennett, C., Cowart, S., Felzien, M., Flores, M., Flores, R., . . . Westfall, J. M. (2013). Boot camp translation: A method for building a community of solution. *Journal of the American Board of Family Medicine, 26*(3), 254-63. doi:10.3122/jabfm.2013.03.120253

The High Plains Research Network and its Community Advisory Council, based in rural eastern Colorado, developed a process to translate scientific evidence-based guidelines and recommendations into accessible messages and improve dissemination. This article lays out the background, development, implementation and results of the CBPR strategies used to develop the Boot Camp Translation Method. Just as “plain” as the language used for translation, evidence suggest that this method is an effective tool for building relationships, engaging patients, and developing culturally relevant materials. [Trust]

Norman, N., Cowart, S., Felzien, M., Haynes, C., Hernandez, M., Rodriguez, M. P., . . . Westfall, J. M. (2013). Testing to prevent colon cancer: How rural community members took on a community-based intervention. *Annals of Family Medicine, 11*(6), 568-70. doi:10.1370/afm.1586

This article describes the experience of members of the High Plains Research Network Community Advisory Council (CAC) going through an intensive training process and tackling a rural community-based intervention for colon cancer. Of note beyond just detailing their experiences, the CAC authors underscore the importance of authenticity, focus, and different understandings of time and pace for the project between CAC and researchers. [Reciprocal relationships]

Page-Reeves, J., Regino, L., McGrew, H. C., Tellez, M., Pedigo, B., Overby, A., . . . Burge, M. (2017). Collaboration and outside-the-box thinking to overcome training-related challenges for including patient stakeholders as data collectors in a patient-engaged research project. *Journal of Patient Experience, 5*(2), 88-91. doi:10.1177/2374373517729506

Arising from the need to overcome challenges to train patients as data collectors in their CER study of diabetes self-management of Latinos in Albuquerque, New Mexico, the authors of this article describe how collaboration and out-of-the-box thinking led to increased project and patient-stakeholder capacity. This article lays out how community engaged design centered around hiring and training data collectors from the community (for many reasons, including language and cultural competence) and how they overcame significant obstacles. [Partnerships]

Sheridan, N., Kenealy, T., Stewart, L., Lampshire, D., Robust, T. T., Parsons, J., . . . Connolly, M. (2016). When equity is central to research: Implications for researchers and consumers in the research team. *International Journal of Integrated Care, 17*(2), 1-5. doi:10.5334/ijic.2512

The authors reflect on their attempts to conduct a research project with equity as a core principle and the challenges they faced. They noted their process and how shared aspirations, priorities, and interests between the researchers and Indigenous community members who are users of the healthcare system did not always match up. The article offers guidance on how to engage communities who have been mistreated while recognizing that there is a need for improvement. [Trust]

Stewart, M. K., Felix, H. C., Olson, M., Cottoms, N., Bachelder, A., Smith, J., . . . Greene, P. G. (2015). Community engagement in health-related research: A case study of a community-linked infrastructure, Jefferson County, Arkansas, 2011-2013. *Preventing Chronic Disease, 12*, e15. doi:10.5888/pcd12.140564

This case study demonstrates how a community-academic partnership developed an enhanced model of community engagement. They focused efforts on thoughtfully building infrastructure, such as a community advisory board, community health workers, health registry, resource directory, and research collaborative, to involve minorities in all stages of research the partnership. This supported them in engaging populations disproportionately affected by health inequities. The article details the types of infrastructure, as well as the successes and challenges of each. [Partnerships]

Teufel-Shone, N. I., Siyuja, T., Watahomigie, H. J., & Irwin, S. (2006). Community-based participatory research: Conducting a formative assessment of factors that influence youth wellness in the Hualapai community. *American Journal of Public Health, 96*(9), 1623-1628.

This paper highlights one of the first successful CBPR partnerships between the Hualapai community and the University of Arizona to combine *emic* (local/native) and *etic* (university/nonnative) perspectives and abilities to develop a culturally relevant formative assessment for public health planning. In terms of the tangible, this project emphasizes the importance of conducting a formative assessment in CBPR, and the article details how to modify research techniques and lays out a method of qualitative data analysis generated by the project. [Cultural competency]

Teufel-Shone, N. I., & Williams, S. (2010). Focus groups in small communities. *Preventing Chronic Disease, 7*(3), A67.

Based on their experience in partnering with small communities and particularly with Native American communities, the authors note how focus groups can be affected by the size of the community. They explore, discuss, and analyze modifications for use in small versus large communities. The article suggests ways in which research teams can utilize a CBPR approach to consider characteristics of the facilitator, recording, questions, setting, timing, recruitment, and confidentiality in ways that ensure and foster engagement in small community settings. [Cultural competency]

Wang-Letzkus, M. F., Washington, G., Calvillo, E. R., & Anderson, N. L. (2012). Using culturally competent community-based participatory research with older diabetic Chinese Americans: Lessons learned. *Journal of Transcultural Nursing, 23*(3), 255-61. doi:10.1177/1043659612441021

This article discusses a combination of CBPR and Vulnerable Populations Conceptual Model (VPCM) to develop and implement a project with older Chinese Americans with diabetes, a population with limited diverse social interaction and environmental and health care resources. This collaborative approach yielded culturally competent research strategies, including developing mutual respect/trust and developing a community sense of ownership, so that all (researchers and community members) learned from each other and were involved in all stages, as well as showing an improvement in overall health of the target population. [Cultural competency]

Personal Perspectives of Partnerships in Research

Articles in this section provide reflections from patient, family, community partners as well as researchers and staff on research partnerships.

Hanson, F., & Hanson, R. (2017). Reflections from a patient and carer on involvement in research and integrating care in the health system. *International Journal of Integrated Care, 17*(2), 16. doi:10.5334/ijic.3088

This article shares personal and concrete observations and suggestions from an elderly patient and caregiver experienced in research and integrating care through their participation in the “iCOACH” (Integrated Care for Older Adults with Complex Health Needs) program. Among other insights from the frontlines, the authors share nine attributes for improving integrated care for older adults.

Purvis, R. S., Bing, W. I., Jacob, C. J., Lang, S., Mamis, S., Ritok, M., . . . McElfish, P. A. (2017). Community health warriors: Marshallese community health workers’ perceptions and experiences with CBPR and community engagement. *Progress in Community Health Partnerships: Research, Education, and Action, (11)3*, 315-320. doi:10.1353/cpr.2017.0037

Articulating the experience, viewpoints, and reflections of the native Marshallese community health workers (CHWs) engaged in research with the local Marshallese community in northwest Arkansas, the authors describe the vital role Marshallese CHWs play in the success of programs and research efforts. The CBPR approach used helped navigate the complicated and traumatic history of Marshallese with the U.S., and empowered native Marshallese CHWs to become advocates. Additionally, native CHWs leveled the power dynamics, built trust, and produced positive health outcomes.

Rasmus, S. M. (2014). Indigenizing CBPR: Evaluation of a community-based and participatory research process implementation of the Elluam Tungiinun (Toward Wellness) program in Alaska. *American Journal of Community Psychology, 54(0)*, 170–179. doi:10.1007/s10464-014-9653-3

Although CBPR is widely acknowledged as an effective strategy for engaging American Indian and Alaska Native communities as research partners, little is known about the community member perspective of the experience. This paper specifically explores issues of implementation, partnership, ownership, and challenges in a project with the Yup’ik Alaska Native Community. Findings revealed much, most notably that what community members described and experienced exceeded outcome variables and coincided with and supported a grass roots social movement in the community.

Thomas, G. R., Kaiser, B. L., & Svabeck, K. (2017). The power of the personal: Breaking down stereotypes and building human connections. *Narrative Inquiry in Bioethics, 7(1)*, 27-30. doi:10.1353/nib.2017.0010

This reflective paper shares sage advice from the Community Advisors on Research Design and Strategies (CARDS) program developed at the University of Wisconsin-Madison School of Nursing on how to navigate interactions between researchers and the community when the two appear to be hindered by assumptions and stereotypes of each other. The authors provide strategies for how “the personal” cannot be drawn out with just any question or activity, but rather efforts must be thoughtful and intentional.

Supporting Participation and Retention of Under-Represented Populations In Research Studies

Articles in this section describe approaches and strategies to improve the participation and retention of typically under-represented populations in health research. The information supports the use of participatory research methods.

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., . . . Hughes, C. (2014). Reaching the hard-to-reach: A systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology, 14(1)*, 1-29. doi:10.1186/1471-2288-14-42

This is a thorough literature review of barriers to sampling, recruiting, participation and retention of socio-economically disadvantaged groups in health research. The authors identify strategies for improving research conditions as well as reflect on several findings, including: the need to acknowledge and extend timeframes when conducting research with community groups, the need to plan for rising resource costs, and the benefit of operating within community partnerships.

Cohn, E. G., Henderson, G. E., & Appelbaum, P. S. (2017). Distributive justice, diversity, and inclusion in precision medicine: What will success look like? *Genetics in Medicine, 19*(2), 157–159. doi:10.1038/gim.2016.92

In this commentary the authors discuss the state of precision medicine today, suggesting that studies may be flawed when minorities are consistently left out, and suggest that precision medicine may fail if three challenges are not addressed. The challenges analyzed include deciding prospectively which groups to include to ensure a meaningful degree of diversity, selecting appropriate criteria for individual inclusion, and designing outreach to the targeted populations.

Erves, J. C., Mayo-Gamble, T. L., Malin-Fair, A., Boyer, A., Joosten, Y., Vaughn, Y. C., . . . Wilkins, C. H. (2017). Needs, priorities, and recommendations for engaging underrepresented populations in clinical research: A community perspective. *Journal of Community Health, 42*, 472-480. doi:10.1007/s10900-016-0279-2

Defining the term “underrepresented” as belonging to a group that is not typically participating in research because of cultural or socio-economic barriers or issues related to physical or cognitive impairment, this study sought to use Community Engaged Research methods to identify research priorities and concerns of underrepresented populations. Community response was clear: there is ineffective communication regarding opportunities in research, widespread uncertainty and misunderstanding of details or options with research participation, high priority for more representation in research, and research teams need training in cultural competence for research teams.

Fouad, M. N., Johnson, R., Nagy, M. C., Person, S., & Partridge, E. (2014). Adherence and retention in clinical trials: A community-based approach. *Cancer, 120*(Suppl 7), 1106-1112. doi:10.1002/cncr.28572

The authors of this article lay out a model of using community health advocates to support and encourage women participants from mostly rural, low-income, and African-American communities to follow through with research protocols so that overall retention for the clinical trial improved. Findings suggest that this model has positive effect, especially in diverse communities.

George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of public Health, 104*(2), e16-e31. doi:10.2105/AJPH.2013.301706

This article presents a systematic review of qualitative and quantitative studies from searches on PubMed and Web of Science. The review delineated barriers and facilitators to participation in research across the racial minorities included in the review. The barriers and facilitators identified included mistrust, lack of access to information, stigma, legal status, altruism, culturally appropriate study design, and cultural congruence.

Getrich, C. M., Sussman, A. L., Campbell-Voytal, K., Tsoh, J. Y., Williams, R. L., Brown, A. E., . . . Neale, A. V. (2013) Cultivating a cycle of trust with diverse communities in practice-based research: A report from PRIME Net. *Annals of Family Medicine, 11*(6), 550-8. doi:10.1370/afm.1543

This article lays out the results of a broad qualitative study conducted by practice-based research networks (PBRNs) focused on determining the process of engaging diverse communities in research. The study identified strategies for successfully recruiting and retaining diverse racial/ethnic communities into PBRN research studies, which they termed the *cycle of trust*. This cycle entails developing and sustaining relationships of trust during four stages: before the study, during study recruitment, throughout study conduct, and after study completion.

Holzer, J. K., Ellis, L., & Merritt, M. W. (2014). Why we need community engagement in medical research. *Journal of Investigative Medicine, 62*(6), 851-855. doi:10.1097/JIM.000000000000097

Rather than ignoring the mistrust of research held by many communities, the authors of this article emphasize that acknowledgement of the valid reasons for the wariness is required to build trust and demands response by researchers to bridge the gaps. This article describes strategies for demonstrating respect for communities with three case studies. Findings discussed include how community engagement leads to better community-researcher relationships and community embrace of the research.

Johnson, D. A., Joosten, Y. A., Wilkins, C. H., & Shibao, C. A. (2015). Case study: Community engagement and clinical trial success: Outreach to African American women. *Clinical and Translational Science, 8*(4), 388-390. doi:10.1111/cts.12264

The case study highlights how using key recommendations from the Community-Engaged Research Core (a CTSA-supported resource) such as (1) convene a Community Engagement Studio, (2) redesign recruitment advertisement, (3) simplify language used to explain scope of study, and (4) provide transportation for participants led to the development of a successful plan. Once implemented, enrollment increased 78% and recruitment goals were met 16 months ahead of schedule. Participant retention and study drug adherence was 100%. The authors concluded that community engagement was essential to the development of an effective plan to improve recruitment of underrepresented groups in clinical trials.

Kaiser, B. L., Thomas, G. R., & Bowers, B. J. (2016). A case study of engaging hard-to-reach participants in the research process: Community advisors on research design and strategies (CARDS). *Research in Nursing and Health, 40*, 70-79. doi:10.1002/nur.21753

This article provides powerful and clear examples about how the CARDS Community Advisors (individuals from under-represented communities) helped researchers understand how research processes and language, tone, and phrasing in communication was actually perceived in the community and the effect on willingness to enroll in studies. Information about the orientation for CARDS advisors and researchers is provided.

McElfish, P. A., Long, C. R., Selig, J. P., Rowland, B., Purvis, R. S., James, L., . . . Narcisse, M. R. (2018). Health research participation, opportunity, and willingness among minority and rural communities of Arkansas. *Clinical and Translational Science, 11*, 487-497. doi:10.1111/cts.12561

Noting a gap in the study of population-based health research rates of rural and minority communities, the authors used questions added to the 2015 Behavioral Risk Factor Surveillance System to understand factors associated with health research participation, opportunities to participate, and willingness to participate from a representative sample of adults in Arkansas. Among other findings, the results indicate no significant difference in willingness to participate in research among racial/ethnic minority communities; in fact, Blacks or Hispanics were more willing to participate.

McSweeney, J. C., Boateng, B., James, L., McElfish, P. A., Robinson, D., Hatley, S. E., . . . Indelicato, N. (2018). Developing and launching a research participant registry. *Health Communication, 1-7*. doi:10.1080/10410236.2018.1465794

To address challenges in recruiting study participants, UAMS worked with Community Advisory Boards (CABs) across Arkansas to develop a representative, ethnically and racially diverse research participant registry. The CABs were involved in each step of the development of the registry and their participation was invaluable to the success.

Oh, S. S., Galanter, J., Thakur, N., Pino-Yanes, M., Barcelo, N. E., White, M. J., . . . Burchard, E. G. (2015). Diversity in clinical and biomedical research: A promise yet to be fulfilled. *PLoS Medicine, 12*(2), e1001918. doi:10.1371/journal.pmed.1001918

This article provides a thorough history of diversity in clinical and biomedical research in the U.S. Special emphasis is placed on suggesting how the National Institutes of Health can use the Revitalization Act of 1993 to increase minority representation in these types of research.

Passmore, S. R., Fryer, C. S., Butler, J., III, Garza, M. A., Thomas, S. B., & Quinn, S. C. (2016). Building a deep fund of good will: Reframing research engagement. *Journal of Health Care for the Poor and Underserved, 27*(2), 722-740. doi:10.1353/hpu.2016.0070

The authors explore the relationships between researchers and minority communities. Looked at through the lens of building social capital as a way to build a "deep fund of good will," the study focused on topical areas of values, solidarity, reciprocity, and enforceable trust. The authors concluded that while many sources of social capital are being utilized, barriers continue to exist, and therefore, they called for structural changes employing sources in an integrated, central and meaningful way.

Related Strategies for Engaging Diverse Partners

The following articles describe methods to engage diverse partners. While not specifically focusing on research, the strategies presented may be useful to research efforts.

DeCamp, L. R., Polk, S., Chrismer, M. C., Giusti, F., Thompson, D. A., & Sibinga, E. (2015). Health care engagement of limited English proficient Latino families: Lessons learned from advisory board development. *Progress in Community Health Partnerships, 9*(4), 521–530. doi:10.1353/cpr.2015.0068

The authors describe the strategies used to establish an advisory board inclusive of a specific diverse population: Latinas with limited English proficiency. Through the use of strategies such as a CBPR-informed approach to partnership and direct invitation by provider, they were able to not just recruit diverse members, but maintain their engagement and achieve results similar to those accomplishments reported by other advisory boards. The article discusses specific aspects of the study, including direct discussions around compensation and feelings/experiences of marginalization.

Goode, T., & Bronheim, S. (2010). *Research: Cultural and linguistic competence checklist for MCH training programs*. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

This resource shares a set of checklists to assess cultural and linguistic competence within maternal and child health training programs. In addition to sharing the checklists, and defining key concepts in cultural and linguistic competence, the article asserts several ways in which such approaches are also warranted in research.

Santilli, A., Carroll-Scott, A., & Ickovics, J. R. (2016). Applying community organizing principles to assess health needs in New Haven, Connecticut. *Public Health Policy, 106*(5), 841-847.

This article describes how a Yale-New Haven hospital partnered with the Community Alliance for Research and Engagement, a research center within the Yale School of Public Health, to employ a community-engaged research approach to community needs assessment. The authors recount how use of this approach generated crucial insights and results. Challenges are reported such as bureaucracy and tight timelines, but recommend this approach as effective for catalyzing and sustaining diverse community engagement, especially in low-income communities.

Sullivan, G., Cheney, A., Olson, M., Haynes, T., Bryant, K., Cottoms, N., . . . Curran, G. (2017). Rural African Americans' perspectives on mental health: Comparing focus groups and deliberative democracy forums. *Journal of Health Care for the Poor and Underserved, 28*(1), 548-565. doi:10.1353/hpu.2017.0039

This article compares two different ways of soliciting community member input—focus groups and deliberative democracy forums. Although deductive analyses identified only minor differences in content, the authors suggest a variety of reasons why researchers should consider using deliberative democracy forums rather than focus groups with marginalized populations, particularly when seeking to mobilize communities to create community-initiated interventions.

General Patient, Family, and Community Partner Engagement in Research

The articles included in this section do not specifically focus on engaging diverse partners. However, the strategies and lessons learned that are discussed may be useful to researchers and partners.

Black, A., Strain, K., Wallsworth, C., Charlton, S. G., Chang, W., McNamee, K., & Hamilton C. (2018). What constitutes meaningful engagement for patients and families as partners on research teams? *Journal of Health Services Research & Policy, 23*(3), 158-167. doi:10.1177/1355819618762960

Using qualitative methods, the authors of this article surveyed patient research partners for their perspectives and recommendations for meaningful engagement. A few of the key recommendations for research leaders include providing a welcoming environment, outline expectations, and recognizing the value of patient partners.

Boaz, A., Hanney, S., Borst, R., O'Shea, A., & Kok, M. (2018). How to engage stakeholders in research: Design principles to support improvement. *Health Research Policy and Systems, 16*(1), 60. doi:10.1186/s12961-018-0337-6

In this paper, the authors used findings from a literature search and a study to develop and describe key design principles about engaging stakeholders in research. Their principles center on three core categories—organizational, values, and practices. The article provides a detailed discussion of recommendations related to each category.

Esmail, L., Moore, E., & Rein, A. (2015). Evaluating patient and stakeholder engagement in research: Moving from theory to practice. *Journal of Comparative Effectiveness Research, 4*(2), 133-45. doi:10.2217/ce.14.79

Beginning with the premises that there is growing interest and demand for patient/stakeholder engaged research and that there is limited evidence that such engaged research is valuable, this article set out to synthesize the actual and hypothesized impacts of such engagement. The authors conclude that there is no consensus as to the major purpose of patient/stakeholder engagement in research or its impact. They recommend specific areas for development of evaluative measures and better reporting of engagement to improve data. Additionally, they suggest that these measures and improved engagement require a culture shift supported by investment by and commitment of researchers and funding sources.

Forsythe, L. P., Ellis, L. E., Edmundson, L., Sabharwal, R., Rein, A., Konopka, K., & Frank, L. (2015). Patient and stakeholder engagement in the PCORI pilot projects: Description and lessons learned. *Journal of General Internal Medicine, 31*(1), 13–21. doi:10.1007/s11606-015-3450-z

This article surveyed 47 pilot projects funded by the Patient-Centered Outcomes Research Institute (PCORI) to characterize and ascertain the impact of patient and health care stakeholder engagement in the planning and conducting of research. In addition to giving an overview of the types, levels, and stages of engagement amongst the projects, the article shares some of the early lessons learned including the importance of continuous and genuine partnership, strategic selection of stakeholders, and accommodation of stakeholders' practical needs.

Manafa, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: A scoping review of the "how" and "what" of patient engagement in health research. *Health Research Policy and Systems, 16*(1), 5. doi:10.11886/s12961-018-0282-4

The authors used scoping review methodology to identify methods and outcomes of patient engaged research over the last ten years. The resulting article reports many findings, however, one of the most important is that while methods of patient engaged research are undoubtedly increasing, much more is needed as to evidence of outcomes. Three key recommendations were indicated: clarification of terminology of patient engaged research for consistency, a predefined, validated framework to support and evaluate, and evaluation frameworks and tools.

Shea, C. M., Young, T. L., Powell, B. J., Rohweder, C., Enga, Z. K., Scott, J. E., . . . Corbie-Smith, G. (2017). Researcher readiness for participating in community-engaged dissemination and implementation research: A conceptual framework of core competencies. *Translational Behavioral Medicine, 7*(3), 393-404. doi:10.1007/s13142-017-0486-0

The authors developed a framework and novel tool for assessing the readiness of researchers to partner with communities specifically in dissemination and implementation research. Through engaging with stakeholders—faculty and staff experienced in clinical and translational science and community stakeholders, they identified 40 competencies within 9 domains that include: being clear, establishing trust, recognizing that the community empowers itself, and being committed.

SELECTED RESOURCES FROM THE FIELD

Manuals and Toolkits

- ▶ The **Examining Community-Institutional Partnerships for Prevention Research Group** was a group of representatives from nine organizations who came together to “develop and evaluate strategies to foster community and institutional capacity for participatory research at national and local levels.” They ultimately wanted to foster implementation of effective approaches in public health and prevention at the community level. They developed a comprehensive curriculum, [Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill Building Curriculum](#) that is broken down into seven units full of step by step instructions and exercises, examples, sample policies, and recommended readings.
- ▶ Nine CBPR researchers from a variety of settings including academic institutions and national organizations serving those experiencing domestic violence created a toolkit that is full of information, strategies, video interviews, and tips. While this toolkit, [Power Through Partnerships: A CBPR Toolkit for Domestic Violence Researchers](#), was not intended specifically for health care researchers, the guidance it offers for partnering with marginalized communities in research is extremely helpful.
- ▶ The **Bureau of Sages at CJE SeniorLife**, with funding from PCORI, is a research advisory board made up of Lieberman Center Community Members, Virtual Senior Center Members, and clinicians, and researchers. Members share experiences, build knowledge, and develop skills for working together to provide voice to the direction, design, and implementation of research on aging. An extensive Manual and a Training Toolkit were developed specifically to run the Bureau of Sages. However, others can use the Manual to review basic principles, guidelines, and activities that have been successful in engaging stakeholders and then make adjustments and adaptations to fit the unique features of and conditions in their own setting and the needs of their target population. Download the [Manual](#) and the [Training Toolkit](#) from the PCORI website.
- ▶ The **Wisconsin Network for Research Support (WINRS)** is an innovative community-academic partnership for research. Of particular interest to WINRS is engaging diverse and typically under-represented community partners in research and in pursuit of that the CARDS® (Community Advisors on Research Design and Strategies) program was created. [Read more](#) about CARDS and other programs and peruse offered services.

One of the newest WINRS resources, the **Patient Advisor Toolkit 1 (PAT-1)**, provides a “comprehensive set of modifiable resources for conducting an orientation with patient advisors. The toolkit provides a complete, step-by-step guide for preparing patient advisors to work effectively with researchers.” The PAT-1 includes eight core modules and four optional modules. [Access the Toolkit.](#)
- ▶ Arising from a PCORI-funded engagement award, **Boston University** and **Boston Medical Center** collaborated with a community advisory board to create a training curriculum. They developed and conducted an evidence-based, community-based training program to address the lack of diverse partner engagement in the research process as well as the lack of sustainable community-based communication and dissemination platforms. The **Connecting Community to Research: A Toolkit** provides practical strategies, useful suggestions, and training modules to engage patients and community members in partnering with researchers. [Learn more and access the Toolkit.](#)

- ▶ **Chicago Health Disparities Center**, a research group at the **Illinois Institute of Technology**, partners with racially and ethnically diverse individuals with mental illness. They have developed valuable resources based on their efforts to reduce disparities in physical health in this population. They house several of their journal articles, manuals, and workbooks including Latino Peer Navigator resources and resources for engaging African Americans as peer navigators and as partners in research. The manuals and workbooks are detailed and provide templates, instructions, and training curriculum for persons with lived experience to develop their capacity to partner with clinicians and researchers. Access resources for [Latino Peer Navigators](#) and for [African American Peer Navigators and Research Partners](#).
- ▶ The **MS Minority Research Engagement Partnership Network (MS MREPN)**, a multi-stakeholder group is dedicated to increasing research participation and inclusion among different ethnic and racial groups so that treatment can be best tailored to each group. Resources include:
 - Information about the Network and three separate toolkits for: **Partners** (patients and their caregivers), **Health Care Professionals**, and **Research Professionals** developed to encourage participation in research are available for download. [Access the Toolkits](#).
 - Also available is a summary of MS MREPN's project funded by a PCORI engagement award and links to project deliverables that include a **Summary of Barriers to Research Participation for Minority Individuals with MS and Knowledge Dissemination Report**. While the focus is on individuals with Multiple Sclerosis, the strategies may be applicable across conditions. [Learn more](#).

Online Portals

- ▶ **CERTAIN Patient Advisory Network's INSPIRE Research Portal** is a robust online library of resources designed for patients and researchers partnering on patient-centered outcomes research studies that actively engage patients in the research process from start to finish. Developed at the University of Washington, the purpose of the portal is to provide easy access to existing tools and resources for this research community. The portal includes resources for patients and researchers. [Access the portal](#).
- ▶ The **Patient-Centered Outcomes Research Institute** created the **Engagement in Health Research Literature Explorer**, a searchable database of literature on engagement. The library can be searched based on topic, stakeholder type, phase of research engagement, and year. The process for how PCORI staff select articles for inclusion is detailed. [Access the library](#).

Reports and Recommendations

- ▶ Through funding by a PCORI Eugene Washington Engagement Award, the UCLA Integrated Substance Abuse Programs created the **Stakeholders' Substance Use Research and Treatment Information Exchange (SSURTIE)** as a way to share knowledge and perspectives on treatment services, create fresh insights, and develop a working patient-centered research agenda for opioid use disorder. Notable is the vast array of stakeholders around the table, those not typically present together including individuals with opioid use disorders, family members, providers, researchers, and policymakers. Their **Stakeholder Engagement Methodology Report: Engaging Stakeholders in Patient-Centered Comparative Effectiveness Research on Substance Use Disorder Treatment** outlines the process, highlights, pitfalls, and lessons learned on the road to meaningful stakeholder engagement. [Download the report](#).

- ▶ This **PAINS Project** report, ***The Patient Voice in Cultural Diversity Training for Patient Centered Outcomes Researchers***, is in direct response to the gap in health care provider and researcher curricula for integrating diverse patient input. Authors included researchers and patients with chronic pain from several research centers and organizations. With funding from PCORI, this report shares findings, explore communication techniques and training plans, and offers recommendations. [Download the report.](#)
- ▶ With funding from PCORI, the **National Hispanic Health Foundation (NHHF)** developed a patient-centered research agenda through a multi-stakeholder PCOR Agenda Setting and Collaborative Planning Meeting. Participants identified ways to increase capacity of Hispanic-serving researchers to conduct inclusive, culturally relevant health research. A comprehensive report, ***National Hispanic Patient-Centered Research Agenda Summary Report and Recommendations*** details ways to increase health research with Hispanics that utilizes culturally appropriate, patient-centered approaches, and thus improves the use and trustworthiness of information to make informed health choices. [Access the report.](#)

